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**DOES INFORMED CONSENT THEORY INFORM NURSING PRACTICE? AN EXPLORATION
OF THE APPLICATION OF INFORMED CONSENT PRIOR TO NURSING CARE
PROCEDURES.**

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I ABSTRACT

Informed consent theorists argue that the function of consent is to protect the patient from unwanted care procedures. It therefore follows that consent is a relevant concept prior to nursing care procedures, all of which have the potential to be unwanted.

It is of note that when the nursing literature is examined, informed consent prior to nursing care procedures is barely mentioned. Attention is focused on the nurses' role in facilitating consent prior to non-nursing procedures. This bias is reflected in both the empirical studies and discussion papers in the nursing journals.

In this study, data were collected through focus group discussion and critical incident technique, in order to explore the way in which nurses approach consent prior to nursing care procedures. Analysis of data provides evidence that consent is often not obtained by those who participated in the study and furthermore, that refusals of care are often ignored. Furthermore, consent is often associated only with surgical procedures and a written form. In addition, participants were often uncertain how to proceed with care when the patient was unable to consent.

Data analysis gives practical illustration to the theoretical argument upon which this thesis is founded. The data illustrate that nursing care can be unwanted and hence confirms that consent is an essential concept in nursing practice. Furthermore the lack of attention given to consent as identified in the data reflects the lack of attention given to consent in the literature review. Consent prior to nursing care procedures is an essential but undeveloped concept.

A new ethos for consideration of consent prior to nursing care procedures is required. Nurses should endeavour to facilitate choice prior to those care procedures, which might be unwanted by the patient.

II TABLE OF CONTENTS

I	ABSTRACT	2
II	TABLE OF CONTENTS	3
III	ACKNOWLEDGEMENTS	8
1	CHAPTER 1: APPLICATION OF THE CONCEPT OF INFORMED CONSENT TO NURSING CARE PROCEDURES	9
1.1	THE HISTORY OF INFORMED CONSENT – FROM NUREMBERG TO NURSING	9
1.2	THE DOCTRINE OF INFORMED CONSENT	10
1.3	THE PURPOSE OF INFORMED CONSENT	12
1.4	THE CONCEPT OF AUTONOMY	12
1.5	THE FACILITATION OF A VALID CONSENT	17
1.6	CONSENT PRIOR TO PROCEDURES, WHICH THREATEN PATIENT AUTONOMY	20
1.7	INFORMED CONSENT AND THE ENGLISH COURTS	22
1.8	PATIENT AUTONOMY AND THE DUTY OF CARE	27
1.9	ACCEPTANCE OF THE PRINCIPLES OF INFORMED CONSENT	32
1.10	CONSENT AND PRE-DEFINED PROCEDURES	33
1.11	RESISTANCE TO THE APPLICATION OF INFORMED CONSENT	35
1.12	INFORMED CONSENT MAY NOT PROTECT PATIENT AUTONOMY	37
1.13	INFORMED CONSENT MAY BE THE BEST PROCEDURAL DOCTRINE THERE IS.	39
1.14	THE IMPLICATIONS OF INFORMED CONSENT THEORY FOR NURSING PRACTICE.	40
1.15	AIMS OF THE STUDY	42
2	CHAPTER 2: DISCUSSION OF INFORMED CONSENT IN THE NURSING LITERATURE	43
2.1	THE LITERATURE REVIEW PROCESS	43
2.2	OVERVIEW OF LITERATURE REVIEW:	43
2.3	STUDIES OF NURSES' ETHICAL REASONING	45
2.3.1	<i>Studies of nurses' ethical reasoning; no specific focus</i>	45
2.3.2	<i>Studies of ethical reasoning in relation to food refusal</i>	48
2.3.3	<i>Summary of studies of nurses' ethical reasoning</i>	53
2.4	STUDIES OF INFORMED CONSENT IN NURSING	54
2.4.1	<i>Studies of informed consent prior to medical procedures</i>	54
2.4.2	<i>Studies of informed consent prior to patient participation in medical research</i>	57
2.4.3	<i>Studies of informed consent prior to participation in nursing research</i>	58
2.4.4	<i>Studies of informed consent prior to nursing care procedures</i>	59
2.5	SUMMARY OF LITERATURE REVIEW	67

3	CHAPTER 3: METHODS OF INQUIRY.....	69
3.1	PHILOSOPHICAL BACKGROUND TO THE STUDY	69
3.1.1	<i>Introduction.....</i>	69
3.1.2	<i>The author's perspective on the study topic.....</i>	70
3.1.3	<i>Summary of data collection methods used in this study.....</i>	70
3.1.4	<i>Identification of a research philosophy to guide data collection and analysis.....</i>	71
3.2	FOCUS GROUP DISCUSSION TO EXPLORE HOW CONSENT IS OBTAINED PRIOR TO NURSING CARE PROCEDURES	73
3.2.1	<i>The use of focus groups in this study.....</i>	73
3.2.2	<i>The development of and rationale behind focus group research.....</i>	75
3.2.3	<i>The group effect in focus group data generation.....</i>	77
3.2.4	<i>Preparation for the use of focus groups.....</i>	79
3.2.5	<i>The sample.....</i>	79
3.2.6	<i>Characteristics of the focus groups.....</i>	80
3.2.7	<i>Access to research sites and invitation to participate.....</i>	81
3.2.8	<i>Defining the questions to be asked in the focus group.....</i>	82
3.2.9	<i>Moderation of the focus groups</i>	83
3.2.10	<i>Commencement of data analysis during the focus group interview</i>	86
3.2.11	<i>Transcription of focus group interviews.....</i>	86
3.2.12	<i>The process of constant comparison.....</i>	87
3.2.13	<i>Identification of the unit of analysis</i>	87
3.2.14	<i>Coding each unit of analysis.....</i>	88
3.2.15	<i>Peer involvement in the coding of data.....</i>	90
3.2.16	<i>The creation of categories.....</i>	90
3.2.17	<i>Reconsidering the name of a category and the allocation of units into a category.....</i>	91
3.2.18	<i>Development of the properties of each category.....</i>	92
3.2.19	<i>Analysis of deviant cases</i>	92
3.2.20	<i>Use of the questions discussed in the focus group in the data analysis.....</i>	92
3.2.21	<i>Member checking.....</i>	93
3.2.22	<i>Delimiting the theory.....</i>	93
3.2.23	<i>Theorising.....</i>	94
3.3	CRITICAL INCIDENT TECHNIQUE TO EXPLORE HOW CONSENT IS OBTAINED PRIOR TO NURSING CARE PROCEDURES	95
3.3.1	<i>The use of critical incidents in the present study</i>	95
3.3.2	<i>The development of the Critical Incident Technique.....</i>	95
3.3.3	<i>The development of the use of the Critical Incident Technique within nursing research</i>	97
3.3.4	<i>The sample</i>	99
3.3.5	<i>Access to research sites and invitation to participate.....</i>	100

3.3.6	<i>Characteristics of nurses who participated in critical incident interviews</i>	102
3.3.7	<i>The process of interviewing</i>	102
3.3.8	<i>Critical incidents or critical happenings?</i>	104
3.3.9	<i>Commencement of data analysis during the interview</i>	105
3.3.10	<i>Transcription of interviews</i>	107
3.3.11	<i>The process of constant comparison</i>	107
3.3.12	<i>Identification of the unit of analysis</i>	108
3.3.13	<i>Coding the critical incidents</i>	108
3.3.14	<i>Peer involvement in the data analysis</i>	110
3.3.15	<i>The creation of categories</i>	110
3.3.16	<i>Reconsidering the name of each category and the allocation of incidents into each category</i>	110
3.3.17	<i>Analysis of deviant cases</i>	111
3.3.18	<i>Development of the properties of each category</i>	111
3.3.19	<i>Coding each critical incident for critical happenings</i>	113
3.3.20	<i>Member checking</i>	113
3.3.21	<i>Delimiting the theory</i>	114
3.3.22	<i>Electronic assistance for data analysis</i>	114
3.3.23	<i>Trustworthiness of the focus group and critical incident study</i>	115
3.3.24	<i>Theorising</i>	117
3.3.25	<i>Summary of the composition of categories derived inductively from the analysis of critical incidents and focus group discussion</i>	119
4	CHAPTER 4: HOW IS CONSENT OBTAINED PRIOR TO NURSING CARE PROCEDURES?	120
4.1	<i>DATA INCLUDED IN THIS CHAPTER</i>	120
4.2	<i>NURSING CARE PROCEDURES CARRIED OUT FOLLOWING MINIMAL OR NO EXPLANATION</i>	121
4.3	<i>PATIENTS ARE OFTEN UNINFORMED ABOUT THEIR CARE</i>	124
4.4	<i>IS CONSENT PRIOR TO NURSING CARE PROCEDURES IMPLIED?</i>	126
4.5	<i>CONSENT IS OFTEN NOT OBTAINED BECAUSE OF PATIENT COMPLIANCE</i>	131
4.6	<i>CONSENT IS NOT OBTAINED BECAUSE PATIENTS DO NOT EXPECT IT</i>	135
4.7	<i>IS THERE A WEB OF EXPECTATION ABOUT HEALTH CARE DELIVERY?</i>	137
4.8	<i>THE WEB OF EXPECTATION DOES NOT APPLY TO ALL NURSING CARE PROCEDURES</i>	139
4.9	<i>INFORMATION IS GIVEN PRIOR TO SOME NURSING CARE PROCEDURES</i>	143
4.10	<i>NURSES FOCUS ON INFORMATION GIVING; NOT CONSENT SEEKING</i>	145
4.11	<i>INFORMATION GIVING AS A TOOL FOR ACHIEVING COMPLIANCE</i>	149
4.12	<i>PATIENTS ARE EXPECTED TO OPT OUT OF NURSING CARE</i>	155
4.13	<i>IS CONSENT OBTAINED IN NURSING WHEN IT IS REQUIRED?</i>	157
5	CHAPTER 5: THE PATIENT WHO IS RELUCTANT OR REFUSES A NURSING CARE	

PROCEDURE	159
5.1 DATA INCLUDED IN THIS CHAPTER	159
5.2 THE PATIENT WHO IS INITIALLY RELUCTANT TO ACCEPT A NURSING CARE PROCEDURE. THE USE OF INFORMATION.....	159
5.3 USE OF NEGOTIATION AND COMPROMISE TO REACH AN AGREEMENT.	165
5.4 INITIAL INFORMATION GIVING AND NEGOTIATION DO NOT ALWAYS RESULT IN THE PATIENT'S AGREEMENT OF THE PROCEDURE.....	167
5.5 FURTHER INFORMATION GIVING. THE POINT OF 'EXPRESSED ACCEPTANCE'	170
5.6 THE ROLE OF PERSUASION	173
5.7 INFORMATION TO FACILITATE CHOICE OR COMPLIANCE?	175
5.8 THE FINE LINE BETWEEN AN 'EXPRESSED AGREEMENT' AND CONSENT	177
5.9 THE PATIENT WHO DOES NOT EXPRESS HIS AGREEMENT TO NURSING CARE PROCEDURES. CARE IS ADMINISTERED BECAUSE IT IS CONSIDERED ESSENTIAL.....	181
5.10 THE PATIENT WHO DOES NOT EXPRESS HIS AGREEMENT TO NURSING CARE PROCEDURES. CARE IS ADMINISTERED FOR REASONS OTHER THAN CLINICAL NECESSITY	190
5.11 THE PATIENT WHO DOES NOT EXPRESS HIS AGREEMENT TO NURSING CARE PROCEDURES AND THIS IS RESPECTED.....	193
5.12 TO WHAT EXTENT DO PARTICIPANTS RESPECT THE PATIENT'S REFUSAL OF NURSING CARE?...	198
6 CHAPTER 6: THE PATIENT WHO IS UNABLE TO CONSENT	203
6.1 DATA INCLUDED IN THIS CHAPTER	203
6.2 NURSES ARE UNEASY ABOUT GIVING CARE	203
6.3 THIS UNEASE IS EXACERBATED WHEN THE PATIENT APPEARS TO RESIST.	209
6.4 THE UNEASE IS EXACERBATED FURTHER IF RELATIVES RESIST.	217
6.5 ARE PATIENTS WHO ARE UNABLE TO CONSENT GIVEN CARED FOR 'IN THEIR BEST INTERESTS'? .	225
7 CHAPTER 7: TO WHAT EXTENT DOES THE CONCEPT OF INFORMED CONSENT INFORM NURSING PRACTICE?	229
7.1 INTRODUCTION	229
7.2 MAIN FINDINGS OF THE STUDY	230
7.3 TRUSTWORTHINESS OF THE STUDY	232
7.4 CONSENT PRIOR TO NURSING CARE PROCEDURES IS AN UNDEVELOPED CONCEPT.....	232
7.5 DEVELOPING A CONCEPT OF INFORMED CONSENT PRIOR TO NURSING CARE PROCEDURES.	236
7.5.1 Principle 1: The initial offer of information.....	237
7.5.2 Principle 2: The further exchange of information.....	238
7.5.3 Principle 3: Implied consent can be considered valid if it is obtained following information giving.	239
7.5.4 Principle 4: Information to facilitate meaningful decision making	239
7.5.5 Principle 5: Persuasion should be employed properly.	239

7.5.6	<i>Principle 6: Decision making should not be subject to the unwanted influence of others.</i>	240
7.5.7	<i>Principle 7: The validity of a patient's refusal of care should be assessed.</i>	240
7.5.8	<i>Principle 8: Nursing care should not be administered if a refusal is valid.</i>	241
7.5.9	<i>Principle 9: The patient's ability to give an informed consent should be assessed.</i>	241
7.5.10	<i>Principle 10: Care should be given in the best interests of patients who cannot consent.</i>	242
7.6	CRITIQUE OF THE PRINCIPLES FOR FACILITATING INFORMED CONSENT PRIOR TO NURSING CARE PROCEDURES	242
7.7	APPLICATION OF THE PRINCIPLES	243
7.8	THE CRUCIAL ROLE OF THE NURSE PATIENT RELATIONSHIP	244
7.9	A NEW ETHOS FOR FACILITATING CONSENT PRIOR TO NURSING CARE PROCEDURES.	246
IV	REFERENCES	250
V	APPENDICES	268
	APPENDIX 1: LETTERS TO THE UKCC AND RCN REQUESTING INFORMATION ABOUT ANY ONGOING WORK ON INFORMED CONSENT IN NURSING.	268
	APPENDIX 2: LETTER PERMITTING ACCESS TO AN ACADEMIC INSTITUTION TO HOLD FOCUS GROUP STUDY	271
	APPENDIX 3: NOTICES OF ETHICAL APPROVAL	273
	APPENDIX 4: LETTERS PERMITTING ACCESS TO A CLINICAL AREA TO CARRY OUT CRITICAL INCIDENT STUDY	276
	APPENDIX 5: LETTER SENT OF INVITATION SENT TO POTENTIAL PARTICIPANTS IN CRITICAL INCIDENT STUDY	282
	APPENDIX 6: THE ADMINISTRATION OF SEDATIVES TO A PATIENT WHO IS UNABLE TO CONSENT	284

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1 CHAPTER 1: APPLICATION OF THE CONCEPT OF INFORMED CONSENT TO NURSING CARE PROCEDURES

1.1 The history of informed consent – from Nuremberg to Nursing

The concept that a patient should give his or her consent prior to a clinical intervention is reported to have been an ethical good since early times (Slater v Baker and Stapleton 1767). However, most accounts of the history and development of the concept of consent commence with the attention given to the significance of consent prior to medical research in the wake of appalling experimentation on human subjects that took place in the Nazi holocaust. This is important because in these accounts, attention is focused on the importance of consent prior to participation in research (Nuremberg Code 1947). In the Nuremberg Code, the absolute requirement that a patient should give his consent prior to involvement in clinical research was laid down.

the person involved should have the legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching....and should have sufficient knowledge and comprehension of the subject matter involved as to enable him to make an understanding and enlightened decision. (Nuremberg Code Rule 1)

This requirement of consent was made with a specific reference to the human subject entering medical research; the idea being that participation in medical research is not directly aimed at benefiting the patient and may involve him or her in additional pain or risk than normally would be encountered. The requirement to obtain consent from a patient prior to his or her participation in research was therefore intended as a safeguard to prevent the patient from being involved in an intervention from which (s)he may not benefit. Participation in a research intervention is intrinsically different from the normal course of clinical interventions, which are carried out in what is considered to be in the best interests of the patient.

Since Nuremberg however, the concept of consent has been applied not only prior to research but also prior to clinical procedures, including nursing care procedures, (U.K.C.C, 2000), (U.K.C.C. 1996) and (G.M.C. 1998). Furthermore, from the general concept of consent, the concept of *informed consent* has arisen; a concept which has been given particular definition in ethical theory as shall be discussed below. An expectation has developed that patients should give their *informed consent* prior to clinical procedures in addition to those associated with

research. Beauchamp and Childress (1994) describe:

in recent years, virtually all medical and research codes of ethics have held that physicians must obtain informed consent of patients before undertaking significant therapeutic or research procedures (p67)

The doctrine of informed consent, and its application to nursing will now be considered.

1.2 The doctrine of informed consent

The concept of informed consent is described by Faden and Beauchamp (1986) who replicate the requirements for consent as outlined in the Nuremberg Code. They define informed consent as follows:

X is an informed consent by person P to intervention I if and only if:

- 1. P receives a thorough disclosure regarding I*
- 2. P comprehends the disclosure*
- 3. P acts voluntarily in performing X*
- 4. P is competent to perform X*
- 5. P consents to X*

(Faden & Beauchamp, 1986) (p275)

Faden and Beauchamp define informed consent as the patient's autonomous authorisation (p274). They emphasise that autonomous authorisation is more than a simple expressed agreement or acquiescence to the proposal by the patient. Faden and Beauchamp argue that mere *assent* to a procedure does not indicate one's consent to it; that it is possible to submit to or comply with the plan of another without any actual agreement. Instead, they describe how, in giving his or her consent, the patient "*actively authorises the proposal in the act of consent*" (p278). In order to give such autonomous authorisation, the patient should be informed, be able to comprehend the information and voluntarily consent to the procedure.

These somewhat demanding requirements for an informed consent are echoed in the later work of Beauchamp and Childress (1994) who describe the same four elements of informed consent:

I) information elements- disclosure and comprehension of information

II) consent elements - voluntary and competent to consent

(Beauchamp & Childress, 1994) (p67)

Faden and Beauchamp (1986) (p275) suggest that the components of informed consent are largely undisputed in the ethical and philosophical literature. However there is debate about the terminology used to define informed consent. Culver and Gurt (1982) (p42) suggest that the term 'informed' consent would be better replaced by the term 'valid' consent. They argue that the information component is just one component of an informed consent; a patient's consent can be 'informed' but not 'voluntary', in which case it would not constitute an 'informed consent' according to the definitions cited above. Furthermore, (McLean & McKay 1981) argue that use of the term informed consent is a tortology; that use of the term consent necessarily means that the patient has been adequately informed (p98). These arguments will not be considered further in this thesis. For the purposes of this thesis, the term informed consent is used to refer to the specific definitions of informed consent given by Faden and Beauchamp (1986) and Beauchamp and Childress (1994) as cited above. Where the term valid consent is used in this thesis, it is used interchangeably with the term informed consent. Furthermore, in view of McLean & McKay's argument that use of the term consent implies that the giver of consent is adequately ¹ informed, where the term consent is used in the text of this thesis², it should be taken to refer to an informed consent. However, it should be noted that in the context of health care, the term consent is often used casually in everyday discussion of patient care. It does not always refer to an informed consent as defined above. The term consent is often used to describe the patient's assent to a procedure that is not necessarily informed. This is evident in the data collected for this thesis. Furthermore, in law, as shall be discussed later in this section, the requirements for a legal 'consent' are less stringent than the philosophical requirements for an informed consent. These points are argued in Sections 1.5 & 1.7. However for the purposes of this thesis, where consent and informed consent appear in the text, the terms can be used interchangeably - that is to refer to the criteria required for an informed consent - unless the context indicates otherwise.

Implied consent is defined in section 4.4. For the purposes of this thesis, implied consent is used to describe a consent as defined above, however it is expressed by implication. Assumed consent is not taken considered a valid consent because the elements of consent are not necessarily present; they are assumed.

¹ The information required for an informed consent is discussed in subsequent sections of this chapters

² In the data collected for this study, where the term consent is used by a participant, its meaning should be taken in the context in which it is given.

1.3 The purpose of informed consent

The purpose of informed consent is to protect patient autonomy or self determination. Kirby (1983) argues:

the fundamental principle underlying consent is said to be the right to self determination: the principle or value choice of autonomy of the person (p70)

Informed consent theorists argue that any intervention undertaken without the patient's authorisation, however benevolent, may infringe that patient's autonomy. It follows that if informed consent is required to protect the autonomy of the patient, then informed consent is required prior to any procedure that may threaten that autonomy. Clearly consent will be required prior to some, but not necessarily all nursing care procedures. Consent is required prior to those procedures which threaten patient autonomy. It is clear that many nursing care procedures have the potential to do so. The data collected in preparation for this thesis illustrates how patient autonomy can be clearly infringed by apparently 'minor' nursing care procedures, which do not carry significant risk. Indeed, even apparently minor procedures might infringe a patient's autonomy. Hopkins (1999) identified how the failure to consult an elderly patient led to severe loss of dignity and choice, even though the intervention itself was substantially benign.

The purpose of informed consent is to protect patient autonomy. Informed consent protects autonomy in two specific ways. First, the requirement for consent ensures that patients are not given treatment without their authorisation. Second, the facilitation of the patient's autonomous authorisation enhances the patient's decision making, increasing his or her autonomy in a positive sense. The concept of autonomy will now be considered further.

1.4 The concept of autonomy

An understanding of what it means to promote the patient's autonomous authorisation requires an understanding of the concept autonomy. However, while informed consent theorists agree that informed consent serves to protect patient autonomy, there is no agreement as to how autonomy is defined. There are many definitions of the term autonomy. The varying interpretations of the concept autonomy is well documented in the literature, (Yeide 1992), (Beauchamp & Childress 1994). First of all, it is important to mention that the meaning of autonomy is context specific. Dworkin (1988) argues:

it is very unlikely that there is a core meaning which underlies all these various uses of the term (autonomy). Autonomy is a term of art which will not repay an Austinian investigation of its ordinary uses. It will be necessary to construct a concept given various theoretical purposes and some constraints from normal uses.(p6)

(Feinberg 1986) describes various uses of the term autonomy as capacity; autonomy as a condition, as an ideal and as a right.(Ch 18). In association with informed consent, autonomy refers to the patient's capacity. That is, the concept of informed consent seeks to protect the patient's capacity for autonomous authorisation.

With reference to autonomy as capacity, there is still no general agreement as to how such autonomy should be defined. This is important as, in the absence of a consistent definition of what amounts to (patient) autonomy, there is no agreed understanding of *exactly* what informed consent should serve to protect.

Some of the definitions of autonomy are presented below. Firstly, no discussion of autonomy would be complete without reference to the work of Kant. Kant's moral philosophy focuses on the importance of moral reasoning. For Kant, freedom "*is the ability to be governed by reason*" (Scruton 1982) (p64). This ability to be governed by reason was referred to as autonomy of the will, to be contrasted with 'heteronomy' of the person whose will is subject to external causes. An action arising from desire or emotion is therefore heteronomous and not autonomous. It is not the intention of this thesis to do justice to the work of Kant. However suffice it to say that Kant's philosophy heralds an introduction of the concept of autonomy as a positive concept. Specific criteria are set out to define autonomy; autonomy is more than being merely 'left alone'.

Contemporary definitions of autonomy are presented below. Faden and Beauchamp (1986), define autonomous action as that which is intentional, understood and undertaken without controlling influences (p238). Savulescu (1994) argues that it is the evaluation of information by the individual that is crucial. Dworkin (1988) argues that autonomy is more than an evaluative or reflective notion and offers another definition of autonomy:

the idea of autonomy is not merely an evaluative or reflective notion, but includes as well some ability both to alter one's preferences and to make them effective in one's

actions and, indeed, to make them effective because one has reflected upon them and adopted them as one's own. (1988) (p17)

There are differing definitions of the term autonomy. However all definitions embrace a positive concept; that is autonomy is more than being left alone. Dworkin (1988) and Frankfurt (1971) develop the concept of first and second order desires in their accounts of autonomy. In discussing the concept of freedom, Frankfurt describes first order desires as unevaluated wishes whereas second order desires are the product of reason, reflection and evaluation of those first order desires. Frankfurt argues that to be free is to act according to desires of the second order, which involve an evaluation of first order desires:

someone has a desire of the second order when he wants simply to have a certain desire or when he wants a certain desire to be his will (p10)

Dworkin argues that autonomy is a second order capacity:

To reflect critically upon one's first order preferences and desires, and the ability either to identify with these or to change them in the light of higher order preferences and values. By exercising such a capacity we define our nature, give meaning and coherence to our lives and take responsibility for the kind of person we are.(p108)

Given the differing definitions of the term autonomy in the philosophical literature, it is not surprising that the term does not have a specific meaning in the nursing literature. Evidence from a series of studies concerning food refusal (Norberg et al, 1988), (Jansson and Norberg, 1989), (Davidson et al 1990) (Norberg et al 1994) and (Jansson et al 1995) suggests that nurses interpret the term in different ways and that this subsequently affects the care that is given. These studies are reported in full in the literature review. The different interpretations of the term autonomy as it is used in the literature is discussed by the author in a separate paper, (Aveyard 2000). Furthermore, data collected for this thesis provides evidence that nurses do not have a common understanding of the term autonomy. This is discussed in the presentation of the data. (Chapters 4,5 & 6).

There are varying different accounts of autonomy as human capacity. However, despite the varying accounts of autonomy, most accounts of autonomy share a common theme. Autonomy is consistently defined as more than freedom from interference. This concept of negative liberty

as articulated by Berlin (1958) is generally rejected as sufficient criteria to ensure autonomy. Instead, those who define autonomy embrace the concept of positive liberty. Each theory sets some – albeit varying – criteria as to what should be considered autonomous action. In addition, as has been demonstrated, some of these criteria set very high standards for determining what is autonomous action. That is, not only is there no consensus of definition, but the concept of autonomy seems impossible to achieve.

Beauchamp and Childress (1994) challenge the appropriateness of setting impossibly high standards before an action is considered to be autonomous, if such a standard is to guide ethical decision making:

to limit adequate decision making by patients to the ideal of fully or completely autonomous decision making strips these acts of any meaningful place in the real world, where people's actions are rarely if ever autonomous. (p122)

This approach is advocated by O'Neil (1989) who observes that any definition of autonomy that is set too high is unrealistic and does not protect the 'finite' rationality of individuals:

unless we take one another's limitations seriously, we risk acting in ways that would be enough to treat "ideal" rational beings as persons, but are not enough for treating finitely rational human beings as persons. (p105)

Dealing with the probable misnomer of fully autonomous actions, Beauchamp and Childress (1994) introduce a concept of 'substantial autonomy' (p123). To be substantially autonomous, the individual should have a substantial degree of understanding and freedom from constraint, not a full understanding or absence of constraint to safeguard patient autonomy.

Beauchamp and Childress accept that the proposal of substantial as opposed to full autonomy does not deal with the question of providing clarity to the meaning of the term autonomy or provide criteria by which a substantially autonomous decision might be assessed:

The line between what is substantial and what is insubstantial often appears arbitrary and therefore our analysis might seem imperilled (p123)

In their defence, they argue that the criteria for substantial autonomy are context specific and

can be understood in terms of 'meaningful decision making'. This approach of 'substantial autonomy' is akin to the approach adopted in law for assessing the autonomy of a patient to give consent. In the judgement in (C (Re) 1994), the courts devised a test for capacity to give consent. The case concerned a 68 year old paranoid schizophrenic detained in Broadmoor who was diagnosed as having a gangrenous leg, from which he would die unless surgery was performed. He refused surgical intervention and the court was asked to consider whether his refusal was valid. The High Court held that an adult has the capacity to consent or refuse (is sufficiently autonomous) if (s)he can:

- a) understand and retain the information relevant to the decision in question
- b) believe that information and
- c) weigh that information in the balance to arrive at a choice.

Both Beauchamp and Childress' account of substantial autonomy and the legal test for capacity can be seen as a pragmatic response to the misnomer of fully autonomous action. However replacing a concept of full autonomy with that of 'substantial' autonomy would have important implications for the practice of obtaining informed consent. Informed consent would seek to protect *only* the patient's substantial (not full) autonomy. The standard required for autonomous decision making would not be an unreachable goal for many people. Clearly this standard setting is a double-edged sword. A standard for autonomous decision making that is set too high may be an unreachable goal. Likewise, a standard that is set too low may be a goal that is reached too easily and thereby does not facilitate sufficiently autonomous decision-making. That is, practitioners are not obliged to expect unattainably high levels of understanding or freedom from coercion before they must consider a patient's decision to be valid.

For the purposes of this thesis, the term autonomous authorisation is regarded as a positive concept, referring to more than freedom from unwanted interference. It is therefore more than the patient giving an uninformed acceptance of a procedure. It is accepted that a fully autonomous authorisation cannot be achieved and that the concept of a substantially autonomous authorisation should be sought. A substantial authorisation entails a process of meaningful decision making. That is, where informed consent is required, it is argued that the nurse has a duty to promote the patient's meaningful decision making about care procedures rather than to impose care procedures without the patient's authorisation.

1.5 The facilitation of a valid consent.

The concept of substantial autonomy is accepted as a pragmatic solution to the impossibility of achieving fully autonomous choice. Despite the lack of consensus concerning the components of autonomous choice, it is argued that the promotion of autonomy entails the promotion of the patient's meaningful decision making, rather than the imposition of a course of events, irrespective of patient choice. In view of this, it is argued that the purpose of informed consent is to facilitate meaningful decision making. The components of a valid informed consent will now be considered.

Firstly, in order to give a valid informed consent to a procedure, the patient must be substantially autonomous or competent to do so. This is discussed above. Secondly, the patient requires information. The information component of an autonomous authorisation (informed consent) will be considered in this section. Thirdly, the patient's authorisation should be voluntarily; that is, given without undue pressure or coercion. The way in which information is given affects the voluntary nature of the patient's decision is discussed in Chapter 5.

Engelhardt (1986) (p271-274) outlines three possible standards of disclosure of information required for an informed consent – professional, objective and subjective. The professional standard of disclosure is determined by the practitioner. The patient receives information according to that regarded as necessary by the practitioner. The objective standard of disclosure is determined by that regarded as necessary by a 'reasonable' group of patients. The standard of disclosure is the reasonable patient's need for information. This standard is also known as the prudent patient standard, (Kennedy and Grubb 1994) (p695). The subjective standard of disclosure refers to the information required by a particular patient. That is, information required by the patient cannot be determined by a third party; it is individual to the particular patient.

Engelhardt (1986) (p274) argues that the 'particular patient' standard of disclosure of information is the standard most likely to facilitate the patient's autonomous authorisation of a procedure. Information is given according to individual need, rather than professionally perceived need or the needs of the 'reasonable' patient. The patient needs information that is relevant to him or her in order to give an autonomous authorisation to the procedure. Furthermore, it is the patient, rather than a third party who can determine what information he or she requires to make a meaningful decision. Although this particular patient standard is not

an accepted legal requirement, as shall be discussed in Section 1.7, Brazier (1992) comments that information requirements should be tailored to the individual patient.

the standard determining how much patients should be told about treatment should be patient- centred. Preferably it should not relate to the mythical reasonable patient but to that particular patient (p88)

In this thesis, it is argued that the particular patient standard of disclosure is the approach to information giving that will facilitate meaningful decision making. It is argued that the amount and type of information required by one patient before he or she can give an autonomous authorisation will be different to another. Some patients require a lot of information before they feel they can authorise a procedure while others require less. An incident described in Chapter 5 clearly illustrates this, (Interview 26, section 5.2). It should not be assumed that a full disclosure of information is always required; what is required is that the patient is given information that is relevant to him or her; that is, for the authorisation to be meaningful.

The provision of information to parents prior to childhood vaccinations further illustrates this point, especially in the light of recent controversy (Goldberg 2000). One parent might be happy to proceed with vaccination following the provision of basic information and reassurance from the practitioner about the safety of the vaccination programme. Another parent might require, for example, details of the studies which initiated the controversy, in order to assess the available information for his or herself. Both parents might be ultimately prepared to authorise the vaccination, however the facilitation of an autonomous authorisation of a procedure is more easily achieved in one circumstance than another.

(Hansson 1998) argues that the quality of consent should vary according to the values at stake in a particular procedure. He argues that the integrity, health and wellbeing of a patient are vulnerable both in clinical and research procedures and that the quality of informed consent should reflect the values at stake. That is, the greater the threat to individual autonomy, the greater the attention that needs to be given to facilitating the patient's autonomous authorisation of the procedure. When the threat to individual autonomy is significant, this should be reflected in the quality of the informed consent obtained.

In this thesis, it is argued that the quality of informed consent should therefore be tailored to the needs of the individual patient. The way in which this can be done is outlined in Chapter 7.

Disclosure of information should reflect individual need and the individual significance of the procedure to the patient. In view of this, the information component of an 'informed consent' should be regarded as flexible. The patient should be offered as much information as he or she requires to make a meaningful decision. The way this can be done is to offer the patient initial information and from then on offer further information to the patient and give this information as it is requested by the patient. The amount of information giving therefore depends on the particular patient's needs.

The patient should be given the opportunity to request further information should he or she choose to do so. This point is particularly applicable to nursing care procedures where it is clearly inappropriate to bombard the patient with all the relevant details of an intervention if he or she does not want such information or has had the procedure before. For a patient to give an informed consent he or she should receive as much information as he or she requires in order to make a meaningful decision. The information component of an informed consent should be flexible; information should be given according to patient need.

The type of information offered to patients requires examination. It is argued that the nurse should be prepared to discuss with the patient details about the intended procedure, the rationale for the procedure, the likely benefits and risks entailed. Given that an evidence base for practice is not available about all nursing care procedures, complete information will not always be available. The nurse should be aware of the extent to which his or her practice is research based and be prepared to explain this to the patient. However, rationale may also be given according to physiological rationale. For example, that the patient needs to be turned because of physiological evidence about tissue damage.

It is suggested that initially, the patient is offered details about what is going to happen. If the patient shrugs the information off or appears uninterested, the nurse can deduce that the procedure is not particularly important to the patient and further information about rationale, risks and benefits is not required. If the patient engages in conversation with the nurse, appears interested in the discussion, the nurse can deduce that further information giving is appropriate. This process is discussed further in Chapter 7.

If a patient refuses all information, it is difficult to argue that the information component of informed consent has been met; the patient has waived the opportunity for involvement in decision making. The extent to which, in this situation, the patient has made an autonomous

choice will not be considered in this thesis. The question as to when an 'informed consent' as defined above is sufficiently informed to constitute a sufficiently autonomous authorisation by the patient is a philosophical question which will not be further addressed in this thesis. For the purposes of this thesis, it is argued that the patient should receive the amount of information required by him or herself in order to make a valid consent to a care procedure. The way in which this can be facilitated is described in Chapter 7.

Information giving may therefore be extensive or minimal. What is important is that the patient is happy to authorise the procedure in the light of the information given. In this thesis, it is argued that a valid consent will be facilitated if the components of an informed consent are met. That is, that the patient is offered as much information as is relevant to him or her about the care procedure, that the patient sufficiently understands the information and that the decision to accept care is voluntary. The relationship between nurse and patient will be instrumental in facilitating this information giving process. This is discussed in Chapter 7.

1.6 Consent prior to procedures, which threaten patient autonomy.

It is argued that the quality of informed consent will vary according to the needs of the patient. It will now be argued that whether informed consent prior to a nursing care procedures is required *at all* depends on whether it threatens the autonomy of the individual.

What is significant for one person may be insignificant for another. For example, a patient who is accustomed to daily bathing by the district nursing team may not perceive being given a bed bath while in hospital as a threat to her autonomy. However a patient who is unaccustomed to such intimate care or indeed has religious objection to such care is more likely to perceive the bed bath as a serious infringement to his or her autonomy. The need for consent will be different in these two cases. Consent should be obtained where it is appropriate rather than by adherence to protocol or policy (Doyal 1998).

O'Neil (1984) suggests that consent should be obtained prior to fundamental actions. She argues:

in human contexts, whether medical or political, the most we can ask for is consent for the more fundamental proposed policies, practices and actions. Patients can no more be asked to consent to every aspect of treatment than citizens can be asked to consent to every act of government. Respect for autonomy requires that consent be possible to

fundamental aspects of actions and proposals, but allows that consent to trivial and ancillary aspects of actions and proposal may be absent or impossible (p176)

It is suggested that this analogy is flawed given that governments are elected and health care professionals are not. However, O'Neil offers an approach to the determination of actions for which consent is required which moves away from consideration of risk or other irrelevant criteria but which is in accordance with the arguments presented in this chapter. In a later article, O'Neil (1989) describes respect for patient autonomy in terms of respect for persons. O'Neil identifies the significant attributes of a consent if personhood is to be respected:

if we want to give an account of genuine, morally significant consent, we need to explain which aspects of actions must be consented to if nobody is to be treated as less than a person. An account of genuine consent must then show how the morally significant aspects of plans, proposals and intentions are picked out as candidates for consent (p109)

Here O'Neil argues that only 'morally significant' aspects of care are identified as candidates for consent. If O'Neil's emphasis on 'fundamental' and 'morally significant' actions are interpreted as those which threaten patient autonomy, then we have an understanding of consent which is associated with clinical procedures which threaten patient autonomy.

Without knowledge of the patient, it is not possible to ascertain that one particular nursing care procedure will not infringe the autonomy of a patient and therefore does not require the patient's consent. Therefore, nurses should assume that all care procedures have the potential to infringe patient autonomy. In view of this, the process of information giving as outlined above should precede all aspects of care giving. The patient should be offered initial information prior to all aspects of care. If the proposed procedure does not infringe the autonomy of the patient, he or she is likely to indicate this by declining further information and or discussion. The practical difficulties in identifying which procedures are significant for an individual patient and which therefore require consent are discussed in Chapters 4 & 7.

Given that it is not possible to ascertain which nursing care procedures will threaten the autonomy the patient, it is argued that a comprehensive list of care procedures requiring consent cannot be pre-defined. While it may be safe to assume that some care procedures will infringe the autonomy of all patients, the reverse will not be true. For example, it is reasonable

to assume that the insertion of a naso gastric tube is a serious infringement to the autonomy of all patients. However the administration of a bed bath may be an infringement to some, but not all patients. In view of this, a list of procedures requiring consent may ensure that consent is gained prior to some procedures which, if undertaken, might infringe patient autonomy, but could not incorporate all. In view of this, where a Trust develops a list of care procedures prior to which the patient's consent is required, this list should not be regarded as exhaustive. This process of obtaining consent prior to nursing care procedures is described in Chapter 7, in the light of the evidence presented in this thesis.

It is argued in this thesis, that consent is required prior to any nursing care procedure that threatens the autonomy of the patient. It is argued that given that infringements of autonomy are individual in nature, it is not possible to pre-identify every procedure prior to which the patient's consent will be required. In view of this, nurses should assume that any care procedure could be unwanted by the patient. The patient's autonomous authorisation is required prior to any procedure which threatens the patient's autonomy. Autonomous authorisation is given after a process of meaningful decision making. The ethical requirement of the nurse is therefore that he or she obtain the patient's consent³ prior to any procedure which might threaten the patient's autonomy.

1.7 Informed consent and the English courts.

The extent to which the law requires the nurse to obtain the patient's autonomous authorisation prior to any procedure that, if undertaken might infringe the patient's autonomy will now be considered. Kennedy and Grubb (1994) discuss the role of the English law in upholding the concept of informed consent as a safeguard to patient autonomy, or self determination:

The ethical principle that each person has a right to self determination finds its expression in law through the concept of consent. Thus, the law relating to consent is of the utmost importance in medical law, serving as it does as the means of protecting and preserving the right of the patient to decide what is to happen to him (1994) (p87)

The area of law, which protects the individual's right to make an informed consent, is the tort

³ Consent should be obtained in an appropriate format. The use of implied consent is discussed in Chapter

of battery. Battery is defined by Fleming (1998) as:

intentionally bringing about a harmful or offensive contact with another person's body
(p29)

It has often been debated whether any nursing or medical procedure should constitute 'harmful or offensive contact'; procedures are carried out in the best interests of the patient. However, landmark rulings have indicated that any touching which is not consented to – however benevolent - may be considered harmful or offensive, because the patient does not want them. In 1988, in his judgement in the case *T v T* (1988), Wood J reinforced this view:

the incision made by the surgeon's scalpel need not be and probably is most unlikely to be hostile, but unless a defence or justification is established it must in my judgement fall within the definition of a trespass to the person (Wood J at 67g)

Kennedy and Grubb (1994) have argued that the correct interpretation of the term offensive may be offered by returning to the aims of the law in this context, which they suggest is to:

protect and preserve people from unwanted touching. The essence of...offensiveness lies, therefore, in the unwanted nature of the touching (p173)

Unwanted touching is unlawful. In view of this, it is necessary to examine the extent to which ordinary every day contact amounts to unwanted touching. The extent to which the tort of battery should apply to everyday contact was considered in the case of *Collins v Wilcock* (1984). This case, unrelated to health care, concerned the restraint of the appellant by a police officer which, it was contended, was not necessary in the execution of the police officer's duty. The court considered whether such touching was unavoidable in the course of every day life. Lord Goff argued:

generally speaking, consent is a defence to battery: and most of the physical contacts of ordinary life are not actionable because they are impliedly consented to by all who move in society and so expose themselves to the risk of bodily contact...so nobody can complain of jostling which is inevitable from his presence...in a busy street
(at 378 d)

Lord Goff argued that these touching fall into:

a general exception embracing all physical contact which is generally acceptable in the ordinary conduct of daily life (at 378 e)

Touching which falls into the context of 'every day life' will not amount to battery. The extent to which this principle can be applied in health care was addressed in the case of *T v T* (1988). This case concerned the lawfulness of carrying out a termination of pregnancy and sterilisation on a woman with learning difficulties who did not have the capacity to consent. In the judgement, Wood J rejected the concept that the touching fell into the context of 'every day life'. The extent to which more minor procedures might fall into this category was considered in the case of *F (F (Re) 1990)*. Referring to the concept of 'every day life', Lord Goff ruled

medical treatment, even treatment for minor ailments does not fall within that category of events. (at 73 G)

Given that treatment for even minor ailments does not fall within the context of every day life, it seems that most nursing care procedures will also not fall under this category. Some touching however might. Giving a patient a cup of tea is likely to amount to 'every day' contact while administering an injection is unlikely to. The range of touching involved in nursing care might be perceived as a continuum, ranging between every day contact on the one hand to procedures falling outside this category on the other. The position of the nurse is therefore a difficult one. He or she has to assess whether the touching falls into the context of 'every day life'. Given the practical difficulties of doing so, the nurse should assume that any touching within a nursing context does not fall within the context of every day life..

Thus, in principle, the courts maintain an allegiance to the concept of patient autonomy or self determination; any touching, which does not fall into the context of every day life, without that patient's consent is potentially a battery. Furthermore, the courts do not limit their application of the principles of informed consent to major procedures or those which are particularly risky. The courts view any unwanted touching as potential battery. Indeed it is the touching rather than any ensuing harm that is of concern here. In view of this, in principle, consent is required prior to any touching which might be construed as a battery by the patient. Clearly this will include some nursing care procedures.

In practice, however, there has been reluctance to charge any health care practitioner with battery. The courts will only do so if consent has not been obtained at all. If the patient claims that he or she had been informed, but not in the detail that he or she would have liked, then the claim is unlikely to be pursued in battery. In the English case of *Chatterton v Gerson* (1981), the requirements for a successful charge in battery were examined. The plaintiff claimed that an operation had been a trespass to her person as she had not been given adequate explanation beforehand and had therefore been unable to make an informed decision as to whether to undergo the surgery. That is, she had been given information, but not in the detail required. The action in battery brought by the plaintiff was dismissed. It was held that:

once the patient had been informed in broad terms of the nature of the intended treatment and had given his consent the patient could not then say that there had been a lack of real consent. (258:a)

Thus, the case of *Chatterton v Gerson* (1981) established an important principle in the law relating to consent. That is, once the patient has been informed in 'broad terms' of the nature of the intended procedure, there can be no action in battery, even if the patient had not been informed of details relevant to his or her individual circumstances, as it is argued, informed consent theory demands. Thus the ethical obligation to give information as it is required by the patient in order that he or she may give her autonomous authorisation to a procedure is not reinforced by a legal obligation.

Failure to give sufficient information to a patient are examined by the courts under the charge of negligence. There are two important implications of using the tort of negligence for resolving disputes concerning informed consent. Firstly, for a claim in negligence to be successful, the patient must be able to demonstrate evidence of harm. A patient can only pursue a claim in negligence concerning the provision of inadequate information if this lack of information resulted in some harm. Lack of information - even if this were to constitute a breach of duty - is insufficient to lead to a successful charge in negligence unless it is accompanied by evidence of harm. In view of this, the tort of negligence does not protect the patient's right to information *per se*. It endorses the patient's right to certain information only in the event of ensuing harm.

The second implication of the use of negligence for pursuing claims concerning the provision of inadequate information, is the continuing, although not exclusive, reliance on the 'Bolam

principle' for determining whether or not the information given constitutes a breach of duty. Bolam v Friern Hospital Management Committee (1957) established the principle that:

A doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art.

That is, even where harm has occurred, the patient will be unable to establish a breach of duty if the care delivered is in line with current standards. Whether an aspect of care amounts to a breach of duty will depend on the current practice at the time. Adherence to the Bolam principle requires that the standard required for disclosure of information is set by the professional rather than the patient. It is the professional rather than the patient who determines the level of information that is given to the patient. Again, this approach does not reflect the patient centred approach demanded by the analysis of ethical principles presented in the previous section. It is fair to comment that in recent years, the courts have not demonstrated absolute commitment to the Bolam principle. In two cases the courts ruled that information should have been given to a patient even though a body of professional opinion claimed that it was not common practice to do so, (Smith v Tunbridge Wells Health Authority 1994), (McAllister v Lewisham and North Southwark Health Authority 1994). Furthermore, in his judgement in the Sidaway case, (1985), Lord Scarman declared his commitment to the right of the patient to determine for himself whether to accept professional advice; that information giving be tailored to the needs of the patient, rather than by standards set by professionals. However, Lord Scarman declared that while commitment to the particular patient standard of disclosure by the courts to be utopian (referred to in Kennedy and Grubb 2000) (p694), he felt that the 'next best thing' to be commitment to the reasonable or prudent patient standard. Therefore, while these cases provide some evidence that the courts are moving towards a patient orientated standard for information giving, commitment to the particular patient standard of information giving is not endorsed by the courts. Kennedy and Grubb (2000) observe that:

Lord Scarman's approach has clearly not endeared itself to the English courts. There remains an obvious deference to the medical profession (p695).

In summary, it is suggested that the nurses' ethical requirement to obtain consent prior to those care procedures which threaten patient autonomy is not reflected in the legal requirement. Any touching, however benign of a patient without consent is potentially unlawful. However, once

the patient has been informed in broad terms of a procedure, an action in battery is unlikely to succeed. The tort of negligence, which requires the existence of harm also does not require a patient orientated disclosure of information. That is, the nurses' ethical requirement to inform the patient according to individual needs is not reflected in law. While the law may be useful to guide nursing practice, nurses' ethical duty exceeds their legal duty. Kennedy and Grubb (1994) comment on the relevance of the tort of battery in health care:

There have been relatively few cases in England in which a patient has successfully sued his doctor for battery. This does not mean that the tort of battery is unimportant. Its greatest significance lies in the fact that it represents a statement by the law of the importance of an individual's right to determine what should or should not be done to his body (1994) (p90)

The involvement of the law is commented on by Wear (1998) who observes that legislation may not be as important as a commitment from clinicians to the concept of informed consent. He argues that:

the valid agendas of informed consent will only be met by clinicians who are sold on and committed to the enterprise. The law can never accurately calibrate nor sufficiently motivate the necessary behaviour by itself (p13)

The legal obligation of the nurse to obtain informed consent prior to nursing care procedures does not reflect the ethical obligations. Although, the nurse must consider that any touching that falls outside the context of 'every day life' is a potential battery, there is no stringent legal duty to inform the patient about the touching. Once the patient is informed in broad terms about the procedure; rather than in the detail required by the patient to make a meaningful decision, the charge of battery is likely to be avoided. In view of this, the nurses' ethical and professional duty to inform the patient in the detail that is required by him or her extends far beyond the legal duty.

1.8 Patient autonomy and the duty of care.

If it is accepted that informed consent is linked with patient autonomy, then consent gained prior to a clinical proceeding is as important in protecting patient autonomy as consent gained prior to involvement in research. Informed consent is a requirement prior to medical and

nursing procedures. Veatch (1981) argues:

some argue that in therapeutic situations a lower standard of consent is called for since the physician is committed unequivocally to serving the patient.... such a commitment is morally questionable... even if a physician were so committed, protecting the welfare of the patient does not override the patient's autonomy (p201)

According to Veatch then, principles of informed consent do not permit acting in the best interests of the patient if to do so were to override his or her autonomy. The obligation to obtain the patient's autonomous authorisation, or informed consent prior to clinical procedures in addition to research, as advocated by ethicists and professional bodies including nursing, requires examination. It may be one thing to demand that a patient give her explicit consent prior to involvement in research - an activity, which does not serve to benefit her. It may be another to require informed consent prior to an intervention, which is carried out in what is considered to be in that patient's best medical or nursing interests. The requirement for informed consent prior to therapeutic interventions reaffirms that the purpose of informed consent has moved away from a regulatory role in protecting the patient from unwanted participation in research, towards a role in protecting the patient from unwanted treatment, *even if the aim of treatment is to benefit the patient.*

Notwithstanding the potential limitations of the ability of informed consent to protect patient autonomy, there is general agreement that the purpose of informed consent is to protect the patient from unwanted interventions. The extent to which the requirement to obtain informed consent affects the clinician's duty of care will now be examined.

In their seminal work on medical ethics, Beauchamp and Childress (1994) identify the four principles (autonomy, beneficence, nonmaleficence and justice) which govern ethical decision-making. The usefulness of these principles remains hotly debated, for example (Seedhouse & Lovett 1992) although they retain a high profile in contemporary ethical literature and their appropriateness in nursing has been acknowledged (Edwards 1994).

Beauchamp and Childress demonstrate commitment to the principles of informed consent through the principle of autonomy. They are also committed to the clinician's duty to care (beneficence) and to do no harm (nonmaleficence). However, they do not suggest that the principle of autonomy should take priority over the others when conflict arises. In later writing,

Beauchamp (1994) argues that the principles are balanced; the principle that should override another will depend on the particular circumstances of the situation. The flexibility of this approach has been widely commented upon, for example, Clouser and Gert (1990) and Lustig (1992). However, many writers, for example Pellegrino and Thomasma (1988) (p20) argue that any ranking of principles is inappropriate and that no principle can dominate in all cases; the principles are interwoven. For example, the principle of autonomy, protected by the concept of informed consent, does not absolve the practitioner from his or her duty of care; that is, to act beneficently, or in the best interests of the patient. Nor does it enable patients to demand care that cannot be accommodated by allocation of resources.

Beauchamp and Childress' four principles approach has not been unanimously endorsed in medical ethics, alternative models of ethical decision making have been proposed, for example, Seedhouse and Lovett (1992). With specific application to nursing, the concept of caring has been proposed as an alternative approach to nursing ethics, (Gilligan 1982), (Gadow, 1985), (Watson 1985). The concept of caring can be seen to offer a feminine orientation to ethics and an alternative to the traditionally masculine concepts of autonomy, beneficence and so on. Gilligan (1982) argues that impartiality inherent in a masculine approach to ethics fosters detachment which *'breeds moral blindness or indifference...and a failure to discern or respond to need'* (p24). Without a caring approach, it is argued, it is not possible to employ moral reasoning or make moral judgements. Furthermore, Leininger (1984), described the beneficent nature of caring and the relationship of caring and human health (p3-15).

There are many critics to the approach of caring as an alternative nursing ethic. DeMoissac and Warnock (1996) and van Hooft (1999) argue that as a concept, caring is undefined,. In view of this, Kuhse (1993) argues that the ethics of 'caring' fails to guide and justify nursing actions while Allmark (1998) argues that caring is not necessarily a virtue. Caring *per se* does not stipulate the moral value of what it is that is cared for and therefore cannot be used as a justification for action. Finally, Fletcher (1997) presents a review of literature which suggests that even if caring could be defended as an appropriate ethical framework within nursing, evidence of caring in practice is often absent.

Despite these criticisms, the concept of 'caring' is well entrenched in the nursing literature. Furthermore, although the ethics of caring is often proposed an alternative to the four principles approach, there are clearly similarities between the concept of care and that of beneficence. Caring is perhaps located *within* a beneficent approach. The precise relationship between the

concepts of care and beneficence is beyond the scope of this thesis. Suffice it to say that the concept of care and beneficence both lie somewhere within the clinician's duty of care for the patient

The relationship between the principles of informed consent and the clinician's duty of care to the patient will now be considered. It is often argued, for example Meaney (1996) and Pellegrino and Thomasma (1988), that the principles of autonomy and beneficence are not necessarily diametrically opposed. That is, although the clinician's duty of care / beneficence is associated with the welfare of the patient, the welfare of the patient will not be enhanced if the practitioner overrides the expressed wishes (autonomy) of the patient in the name of 'beneficence'. This sentiment was articulated by Mill (1859):

Neither one person nor any number of persons is warranted in saying to another human creature of ripe years, that he shall not do with his life for his own benefit what he chooses to do with it. He is the person most interested in his own well being (p84)

This principle is echoed in contemporary writing. Indeed as Doyal (1998) argues

To fail to respect the autonomy of competent people is to inflict harm on them that is just as morally unacceptable as direct physical or mental harm (p1001)

Brazier (1992) asserts a similar view. She argues that facilitating patient choice is incorporated within a duty of care.

Within such a relationship of trust the doctor's duty would be to make available to the patient that information which it seems likely that individual patients would need to make an informed choice on treatment. Such a change is desirable not just to endorse patient's rights but also to enhance patient care (p88-9)

If this argument is accepted, facilitating a patient's consent is a component of a beneficent / caring philosophy of care. However, application of informed consent theory implies that when the beneficent practitioner proposes a care procedure, it cannot be implemented without the consent of the substantially autonomous patient. In this specific situation, the principle of beneficence cannot be applied against the wishes of the autonomous patient

Indeed, many writers argue that the process of informed consent is a useful vehicle for deciphering the care and treatment that are in the best interests of the patient. That is, the welfare of the patient can be enhanced by finding out his or her care preferences. For example, Wear (1998) argues that in view of the anonymity of modern medicine, the health care professional cannot profess to know (if indeed he could in earlier times) the best interests of the patient:

it may still be hard to argue that the physician can determine the patient's best interests – he is often a stranger to the patient and often too little time (p32)

Likewise, Engelhardt (1986) argues of the need for informed debate (and eventual consent seeking) prior to any clinical intervention without which the clinician cannot achieve an understanding of the best interests of the patient. He refers to the patient as a “*stranger in a strange land*” (p256).

Katz (1984) describes how the act of mere disclosure of risk to a patient prior to a procedure may not increase his understanding unless it is accompanied by discussion. Only then can the real interests of the patient be ascertained. Katz argues that it is the doctor's duty to facilitate discussion:

doctors are obligated to facilitate patient's opportunities for reflection to prevent ill considered rational and irrational influences on choice (p122).

Similarly, Wear (1998) emphasises that the role of the clinician is to establish the patient's beliefs and not merely to identify them. That is, the patient needs time to discuss and reflect on care options with the clinician and should not be expected to arrive at a decision without a chance to do so. Wear argues:

we can hardly expect patients' views to be adequately worked out regarding unanticipated and extraordinary scenarios (p45).

It is for these reasons then that many commentators on medical ethics refer to a process of ‘assisted autonomy’ whereby the clinician and patient discuss care options together as opposed to a process whereby the patient decides alone. This is a process advocated by Veatch (1995) and Savulescu (1995), who argues that it is the duty of the health care provider to evaluate and

recommend the course of action that the patient, all things considered, ought to take, rather than to provide facts alone. Savulescu describes this as a process of *rational non-interventional paternalism*, which differs from traditional paternalism in that interventions must nonetheless be authorised by the patient. Thus, assisting the patient to make a substantially autonomous decision can be regarded as part of the clinician's beneficent duty, (Botros 1991).

Furthermore, in addition to facilitating patient decision making, there is also evidence that information prior to a procedure may be beneficial in terms of relieving a patient's discomfort and anxiety, (Hayward 1975), (Wilson-Barnett 1979).

Informed consent theory does not allow the beneficent physician to proceed with a care procedure in the absence of the patient's consent. However this does not necessitate that patient autonomy and clinician beneficence are diametrically opposed. There is indeed a strong argument for proposing that respect for the welfare of the patient necessarily incorporates respect for his or her autonomy.⁴ Even where it may not, the two concepts are probably most usefully understood as intertwined.

1.9 Acceptance of the principles of informed consent

Acceptance of the doctrine of informed consent necessitates a shift in the ideology of health care provision. To the clinician's duty of care to the patient is added the requirement to obtain the patient's consent. The health care provider's duty to administer appropriate care can, with certain exceptions, be activated only on the patient's authorisation.

Examination of the medical and nursing literature documents provides evidence of an emerging climate of acceptance of informed consent over recent decades. Initial hostile attitudes towards the concept of informed consent paramount in the literature, for example, in the early 1980s have been largely replaced, with minor altercations, by positive acceptance and discussion of different applications of the doctrine in the year 2000.

This acceptance is consistent with current trends in health care policy. Recent initiatives in public policy have aimed to engender patient choice and provider accountability. One of these early initiatives was The Griffiths Report, (Department of Health and Social Security 1984) which endorsed the concept of accountability within the structure of the NHS. This was

⁴ I am indebted to Dr A. Cribb for his insights on this point

followed by a publication by the NHS Management Executive (1990), in which the requirement to seek the consent of the patient prior to an intervention was embraced as a basic principle of health care.

Patients are entitled to receive sufficient information in a way that they can understand about the proposed treatments, the possible alternatives and any substantial risk, so that they can make a balanced judgement. (p2)

This was closely followed by the Patient's Charter, (Department of Health 1991) which gave explicit and enforceable rights to patients as consumers in terms of their expectations and experience of health care provision. The recent publication *The NHS, Modern and Dependable*, (Department of Health 1997) reinforces the prevailing attitude of the patient as consumer who, as identified in earlier publications has a right not only to information, but to consent and withdraw consent from health care interventions.

The principles of informed consent are consistent with current health care policy emphasising the importance of patients' rights and choice in health care. A paternalistic approach from the health care provider is replaced by an approach that advocates greater patient involvement in care delivery. This approach has been endorsed by the nursing professional bodies, for example The U.K.C.C (2000) who argue that all nursing care procedures be carried out "*within a framework of informed consent*"(p15).

1.10 Consent and pre-defined procedures

Despite this expressed acceptance of the principles of informed consent, it is of note that when the doctrine of informed consent is applied to clinical practice, it is often assumed that consent is required only prior to major clinical interventions or where the intervention presents significant risk to the individual. This was the assumption made by many participants in this study as shall be demonstrated. Furthermore, it has been the approach of many commentators of medical ethics to limit the requirement for consent to certain procedures which entail a degree of risk or potential harm to the patient, irrespective of the extent to which they threaten patient autonomy. For example, Kirby (1983) associates the requirement for informed consent with the degree of risk a procedure entails. He argues that consent should be obtained:

before any diagnostic or therapeutic procedure...which may have any reasonable possibility of harm to the patient (p69)

Similarly, Williams (1997) discusses whether or not consent should be sought prior to blood transfusion. He claims that there is no doubt that the patient should be informed about the transfusion; what he claims is in question is whether he should be required to give his consent:

the controversy does not hinge on the need to inform patients adequately – that is accepted – but centres on two issues. The first is whether consent in this instance is appropriate – that is, does transfusion of blood or blood products carry a material risk? The second is whether the consent obtained would be valid. (p380)

Williams may be right in separating information giving from consent seeking, but to suggest that consent is required only if a procedure (blood transfusion) carries a material risk is to associate the principles of informed consent with harm and not with respect for autonomy.

Dagi (1994) suggests a new paradigm for informed consent which focuses on assuming different levels of consent according to the level of risk or alternative options available to the patient. The more risky the procedure, the more informed the disclosure will be. Likewise, where alternative options are present, discussion will be more extensive.

While it may be so that certain procedures require a greater amount of prior counselling than others, this should not be regarded as synonymous with the requirement for consent.

Moving away from considerations of risk, Wear (1998), restricts the interventions prior to which consent should be sought to those where the intervention is not 'clearly indicated'. According to Wear, consent becomes less important when an intervention is 'clearly indicated'; that is, where there is no conceivable alternative to the proposed care. Presumably, Wear does not consider non treatment to be a viable alternative. He describes:

in such cases it is rather strange to suggest that the physician should approach the patient as if he really had a decision to participate in , or that a subsequent refusal should be seen as an exercise in personal autonomy, not a cause for alarm (or suggestive of patient incompetence) (p68)

Clearly, patient autonomy can be breached even if there is but one sensible treatment option. The case of the Jehovah Witness who refuses life saving blood products is an obvious case in point.

There may be pragmatic reasons for the restriction of informed consent requirements to clinical interventions that entail risk, or are not clearly indicated. It may be considered too onerous a task to seek consent prior to every care procedure, even if to do so were necessary.

Furthermore, the infringement of autonomy might be considered too minor to be of serious concern. The participants who took part in this study identified the inappropriateness of seeking informed consent prior to each and every procedure (Chapter 4). However in this thesis, it is argued that it is not possible to predefine every care procedure prior to which consent should be sought. A more comprehensive approach to consent is required so that consent is sought prior to procedures that threaten patient autonomy, rather than prior to a predetermined list.

Furthermore, the requirement for obtaining informed consent need not be onerous. This will be discussed in Chapter 7.

It is argued that the common association of consent with procedures in which there is anticipated risk or where there is a lack of alternative care is unsatisfactory. As a result of this association, consent prior to nursing care procedures is often not acknowledged. This is evident in the literature reviewed in Chapter 2. Clearly, patient autonomy can be infringed irrespective of whether or not risk is attached to a clinical procedure, or whether the procedure is considered clinically indicated. The requirement for consent is instead better understood as a requirement prior to care situations, which threaten individual patient autonomy. If consent is a means of protecting autonomy, then consent should be obtained in an appropriate format prior to any intervention which seriously threatens patient autonomy, irrespective of the degree of risk the procedure entails.

1.11 Resistance to the application of informed consent.

Acceptance of the principles of informed consent has not been achieved without opposition. Faulder (1985) argues that emphasis on patient autonomy may not be easily accepted by clinicians. She argues that many clinicians may not regard respect for patient autonomy as integral to their beneficent duties:

many doctors...who base their philosophy of action on their Hippocratic oath...to act in the best interests of their patients, will argue that the obligation to seek informed consent is often not necessary, sometimes undesirable and frequently impossible. In short they do not accept they have this obligation (p22)

Wreen (1991) argues that many people are still uncomfortable with the idea that the application of the doctrine of informed consent legitimises the patient's refusal of treatment, which he argues can be seen to be unreasonable:

when autonomy is isolated from other values, an autonomous patient might refuse treatment for utterly trivial, laughably whimsical or grossly irrelevant reasons. A paternalistic response then gains markedly in intuitive appeal and may even present itself as a viable moral agent (p128)

Tobias and Souhami (1993) argue that application of informed consent principles might not be considered beneficent, asserting that is often unnecessary, even cruel to explain minor, but significant risks to patients which do not eventually materialise.

On a practical level, Sulmasy et al (1994) report on the inefficient nature of the informed consent process. They describe their study in which many patients remained unaware of many risks entailed in a procedure, despite having been informed and given their 'consent'. Many commentators have observed that patients are rarely in a position to make an informed consent, for a variety of practical reasons, (Lavelle-Jones et al. 1993), (Blackmore 1989). In addition, determining whether a consent has been 'informed' has practical difficulties. Gillet (1989) comments:

it may be difficult to ascertain in any particular instance that this standard has been satisfied and therefore it cannot straightforwardly be used to frame policy for epistemological reasons (p117)

There is evidence that the idea that beneficence is associated with respect for patient autonomy is not universally accepted. In addition, practical difficulties with the application of informed consent principles lead others towards a sceptical approach to the role of informed consent theory.

Even those committed to the idea of patient autonomy do not agree that it can be enhanced only by application of the principles of informed consent. They argue that in some situations, care procedures can be carried out against the wishes of a patient if these are expected to lead to health improvements and therefore the eventual enhancement of the patient's overall autonomy. These arguments suggest that what is important is the enhancement of the patient's

potential or eventual autonomy, even if this means disregarding his (less than optimally autonomous) but possible sufficiently autonomous decisions. For example, Strasser (1988) examines the argument that in certain cases, provision of information may actually infringe patient autonomy, leading the patient to make decisions which do not reflect his true values. Thus the patient is not acting autonomously. In view of this, information can be legitimately withheld without any infringement to the patient's real autonomy, if the patient's autonomy will be ultimately enhanced. Furthermore, by the same reasoning, it can be argued that if a care procedure is anticipated to enhance the autonomy of a patient, so it can be implemented without the patient's consent.

Similarly, Davis and Underwood (1989) argue that nursing care can be administered even in the face of a patient's apparent refusal, if the care will lead to an eventual enhancement of patient autonomy. They do not limit their proposal to patient decisions which are not considered to be substantially autonomous.

Arguments which focus on the patient's ultimate autonomy are described by Strasser (1988) as a 'new paternalism'. Strasser examines but finally rejects these arguments.

if the claim that patient autonomy ought to be respected is going to mean anything, then we cannot override the patient's rational, autonomous decisions merely because those decisions, if carried out, would not promote that individual's autonomy...were we to adopt such a rationale for overriding individual's decisions about their own welfare, we could justify so many incursions into the domain of decisions appropriately left up to the individual, that there would be few choices which the individual would be allowed to make (p15-16).

The arguments behind a 'new paternalism' are rejected by Strasser and clearly by those who advocate informed consent theory. However, these arguments are often rehearsed. Indeed those who participated in this study appeal to these arguments, (Chapter 4). These arguments indicate that commitment to the concept of informed consent is not universal. This wavering commitment should be acknowledged when the process of obtaining informed consent is considered.

1.12 Informed consent may not protect patient autonomy

It is argued that informed consent serves to protect patient autonomy, but that a modified concept of autonomy (substantial autonomy) may be a useful guide in determining a working

meaning of autonomy. However the claim that informed consent does in fact protect the patient's substantial autonomy may be challenged. Informed consent may fail to protect patient autonomy in several ways. Firstly, failure on the part of the health care practitioner to give sufficient information to a patient about the likely cause of events may result in the patient being unable to give a consent to the standard required. The patient may therefore not be considered 'substantially autonomous enough' to give consent. In the case of *Re T* (1992), the daughter of a Jehovah Witness was injured in a road traffic accident. She was 34 weeks pregnant and agreed to a caesarean section. After a visit from her mother, she told the medical staff that she would not agree to having a blood transfusion, having first been told that alternative options to blood transfusion were available. Her child was still born and T lapsed into unconsciousness. Her wishes to refuse blood transfusion were upheld until her father and boyfriend went to court to challenge the validity of this refusal. It was alleged that she had not been warned about the potential seriousness of her condition and when her condition deteriorated, it was argued that her 'refusal' had not been based on adequate information about the gravity of her condition. The court held that T's refusal were flawed by impaired capacity, lack of information and undue influence. Blood transfusion was given.. It could be argued that T. should have been informed about the likely course of events to follow and should have been given the full information upon which to make a decision. However, giving information about all eventualities is clearly not always possible. When such cases inevitably arise, practitioners are clearly in a dilemma.

Secondly, there is another procedural difficulty with the doctrine of informed consent that may not be so easily overcome by the provision of adequate information. This difficulty concerns the standard set at which a patient is considered to be able to give a valid consent; an ability that may be affected by a variety of factors including mental impairment, shock following a diagnosis or pain.

Even if the stringent requirements for full autonomy are tempered by the reasoning of Beauchamp and Childress (1994) for substantial autonomy, many patients may still be unable to make a valid consent of the standard demanded. Clearly, the process of setting a standard for substantially autonomous patient decision making also sets a standard at which patient decisions are considered not to be substantially autonomous. While the doctrine of informed consent requires that health care professionals do not proceed without the consent of a patient who is able to give it, it cannot apply to patients who are unable to give a substantially autonomous consent. Indeed, to act according to the decision of a patient who is unable to make

a meaningful choice would be to undermine the concept of informed consent, (Botros 1991).

Rather than seek consent from those unable to give it, many ethicists argue that it is permissible to override the decision of a patient who is unable to make a substantially autonomous choice. For example, Pellegrino and Thomasma (1988) argue:

Physicians may therefore act over the objections of patients to preserve life or prevent serious harm, when patients are senile, confused, depressed or otherwise incapacitated in their abilities to make autonomous judgements (p16)

The legal position with respect to patients who cannot give consent also reflects this position. The court in the case of *Re F* (1990) ruled that when a patient cannot consent, care can be delivered without incurring a charge of battery if that care is in the best interests of the patient. In view of this, practitioners are therefore required to assess whether the decisions of a patient are substantially autonomous. With this requirement, therein lies the possibility for the situation described famously by Berlin (1958) as a “*monstrous impersonation*”. One person (the health care professional) acts possibly against the expressed wishes of another (the patient) when he claims to know the true needs of the other better than the person himself:

I am then claiming that I know what they truly need better than they know it themselves. What, at most, this entails is that they would not resist me if they were rational, and as wise as I and understood their interests as well as I do. (p18)

Thus while informed consent theory serves to protect the ‘substantial’ autonomy of those considered able to consent, it can also legitimise the overruling of a ‘consent’, or more likely the withholding of consent, that is not considered substantially autonomous. While in many cases, the assessment whether a patient’s decision is substantially autonomous will not be in dispute, in other cases it might be. Whether a patient’s consent to health care is respected may therefore rely on the assessment by the practitioner of his ability to consent. When a poor assessment is made or no agreement can be made about the ability of the patient to consent, the concept of informed consent, which should serve to protect patient autonomy may in fact undermine it.

1.13 Informed consent may be the best procedural doctrine there is.

There are conceptual and practical difficulties with the application of the principles of informed

consent which may not be easily overcome. Despite this, informed consent theory is widely but not universally proposed as an acceptable process by which patient decision making in health care is facilitated. It may be that in moving away from the ethos of medical paternalism, informed consent is the best procedural doctrine we have got.

1.14 The implications of informed consent theory for nursing practice.

There is an ethical and legal requirement for nurses to consider informed consent prior to nursing care procedures. From an ethical perspective, informed consent serves to protect patient autonomy and to facilitate the patient's autonomous authorisation of a procedure. The principles of informed consent thus embrace both the negative concept of autonomy - freedom from interference – and the positive concept of autonomy – the facilitation of the patient's meaningful decision making. Informed consent is therefore required prior to any procedure which, if undertaken without consent would threaten the patient's autonomy. It is argued that the quality of informed consent should be flexible and tailored according to individual patient need. As described earlier in this section, if the potential infringement is minor and the patient does not request copious amounts of information, the information element in the 'informed consent' will not be extensive. However, what is important is that the amount and type of information should be directed by the patient, not the nurse. The consent should be as informed as the patient wants it to be. Given the obvious potential for nursing care to present a threat to patient autonomy, 'informed consent' is clearly a highly relevant concept prior to nursing care procedures.

From an legal perspective, the principles of self determination are protected by the laws of battery. In principle, any touching is a potential battery, the defence for which is the patient's consent. In practice however, the charge of battery is rarely pursued and is unlikely to be successful once the patient has been informed in 'broad terms' about the procedure. The tort of negligence does not protect the patient's right to self determination. That is, the law does not demand that the patient's consent be 'informed' in the manner required from an ethical perspective.

Application of informed consent theory to nursing practice requires the nurse to apply the following principles to practice when facilitating patient decision making.

Principle one:

The nurse should obtain the patient's consent when to proceed without consent would threaten a patient's autonomy. The approach to seeking consent should be patient centred. The

requirement to obtain consent should be determined by individual patient need as should the information given. The nurse should ensure that in these instances the consent is valid; that the patient is aware and informed about the procedure and free from coercive interference.

Principle two:

The nurse should respect the patient's substantially autonomous refusal.

Principle three:

The nurse should not seek consent from those patients who are unable to give it. The patient should be cared for in his or her best interests.

There is a strong theoretical argument for the application of informed consent principles prior to nursing care procedures. However the theoretical argument supporting the application of informed consent theory prior to nursing care procedures is not sufficient. Theoretical argument must be usefully and appropriately applied to nursing practice if the theory is to enhance patient care. The application of informed consent according to these principles will be examined in this thesis. Although the doctrine has been accepted by nursing professional bodies, it may not be easily applied in practice. The application of informed consent theory must be specific and appropriate to nursing care. This is essential if the principles of informed consent are accepted by those at the front line of care.

This chapter has sought to demonstrate that seeking informed consent, as defined in the chapter, is an ethical requirement in nursing care. However details of its application prior to specific nursing care procedures have not been discussed. These will be discussed as the work of this thesis progresses. This thesis describes a study of the way in which informed consent is obtained prior to nursing care procedures. However, consent is a complex interaction which may be difficult to detect. Furthermore, the method of obtaining consent must be appropriate to the context in which it is gained. For these reasons, consent may not be gained in exactly the way that is prescribed in the theory. The application of informed consent theory to nursing practice is discussed throughout this thesis. The empirical data collected from the qualified nurses who participated in this study is used in two ways. Firstly as evidence concerning how consent is obtained prior to nursing care procedures. Secondly as a springboard for discussion concerning how consent could or should be obtained in accordance with the principles outlined in this chapter. The thesis has two aims:

1.15 Aims of the study

- To examine how consent is obtained prior to nursing care procedures.
- To explore the ways in which consent could be approached by clinical nurses.

2 CHAPTER 2: DISCUSSION OF INFORMED CONSENT IN THE NURSING LITERATURE

2.1 The literature review process

The nursing literature was examined in order to identify how respect for patient autonomy and informed consent prior to an aspect of nursing care are understood and implemented by nurses in clinical practice. It was anticipated that many studies might provide an illustration of the ways in which respect for patient autonomy and informed consent prior to a nursing care procedure are understood by nurses in clinical practice, but that these may not be easily identified as such. Data specifically relevant to this study may be 'hidden' within other studies. For this reason the literature search strategy did not focus solely on respect for autonomy or informed consent prior to nursing care procedures but encompassed a wide range of literature related to ethics in nursing. The following search strategy was employed to identify literature on informed consent. A CINAHL and MEDLINE search dating back to 1985 was undertaken at the commencement of the study (1996). Subsequent to this initial search, the search was repeated yearly. In addition, hand searches were undertaken of the Journal of Advanced Nursing, the Journal of Medical Ethics and Nursing Ethics (1990-2000). As a further searching strategy, reference lists from relevant articles were scrutinised. As an additional search strategy, the United Kingdom Central Council for Nursing, Midwifery and Health Visiting and the Royal College of Nursing were contacted for information concerning any ongoing work in the area of consent prior to nursing care procedures. (Appendix 1).

2.2 Overview of literature review:

The review of the nursing literature is divided into the following sections:

1. Studies of nurses' ethical reasoning.

- Studies of nurses' ethical reasoning
- Studies of nurses' ethical reasoning in relation to food refusal

2. Studies of informed consent

- Studies of informed consent prior to medical procedures
- Studies of informed consent prior to medical research.
- Studies of informed consent prior to nursing research.
- Studies of informed consent prior to nursing care procedures.

Summary of the content of the literature reviewed

1. Studies of nurses' ethical reasoning.	Authors	Type of study	Main findings
Studies of nurses' ethical reasoning	(Ekman & Norberg 1988) (Elander et al. 1993) (Lutzen & Nordin 1994) (Robertson 1996) (Holm 1997)	Interviews with nurses about their approach to ethical situations in clinical practice	Studies illustrate a tension between concern for autonomy and clinician beneficence. No overriding emphasis on autonomy.
Studies of nurses' ethical reasoning in relation to food refusal	(Norberg et al. 1988) (Jansson & Norberg 1989) (Davidson 1990) (Norberg et al. 1994) (Mattiasson & Andersson 1994) (Jansson et al. 1995) (Day et al. 1995) (Mattiasson & Andersson 1995)	Scenarios given to participants for discussion concerning the care of a patient who refuses to eat. Most studies compare the care of an alert patient with end stage cancer with a patient with dementia.	Studies consistently identify that participants are prepared to respect the refusal of food of a terminally ill patient. Participants are divided as to whether the refusal of a patient with dementia should be respected. The studies indicate hypothetical responses only.
2. Studies of nurses' understanding of the informed consent process			
Studies of informed consent process prior to medical procedures	(Davis 1988) (Whalen 1984) (Carney 1987) (Kee 1995) (Costa-D'sa 1996)	Interview or questionnaire studies with nurses to discuss vignettes concerning informed consent prior to medical procedures.	Studies illustrated a sketchy understanding of informed consent process. Patients were often steered towards care options.
Studies of informed consent process prior to medical research	(Davis 1989) (Nusbaum & Chenitz 1990)	Interview study Observational study	Nurses unsure about their role in facilitating consent Researchers concerned about recruiting into trial, not obtaining consent
Studies of informed consent process prior to nursing research	(Duffy et al. 1989)	Observational study of patient recruitment into research	Potential participants required much time before they agreed to participate in a research study. Those who refused did so immediately.
Studies of informed consent process prior to nursing care procedures	No specific studies identified. (McCormack 1998) (Levy 1999a) (Levy 1999b) examine patient choice prior to discharge from hospital and childbirth	Observational and interview studies	Concept of patient choice is questioned. Patients are directed to accept the prescribed care.

2.3 Studies of nurses' ethical reasoning

2.3.1 Studies of nurses' ethical reasoning; no specific focus

Studies fall into two main categories. These studies either use participant response to a given vignette or are exploratory studies in which difficult ethical situations are identified and discussed by participants. In the vast majority of the studies, consent prior to nursing care procedures is not addressed; that is, it is not a factor in the vignette nor is it identified by participants in the exploratory studies as a difficulty recently encountered, (Astrom et al. 1995), (Uden et al. 1992), (Stauffer 1993), (Soderberg & Norberg 1993).

Five exploratory studies were identified in which participants were invited to recount difficult clinical situations. In these studies, the tension between respect for patient autonomy and considerations of beneficence were a main theme.

In a Scandinavian study, Lutzen et al (1994) interviewed 14 experienced psychiatric nurses. The participants were asked to relate an incident in which they were unsure about the right action to take. The interviews were taped and transcribed. The researchers commented that participants were motivated by a concern to 'do good' rather than a concern to allow patients to take their own decisions:

In this study the nurses' actions were motivated by 'not wanting harm to come to the patient' and 'doing good'. This indicates that psychiatric nurses interpretation of the psychiatric patient's rights and their knowledge of formal codes of ethics needs to be further investigated. (p105)

In this study, nurses' commitment to 'doing good' rather than promoting client decision making may be accounted for in terms of the varying ability of the clients to authorise the proposed care. That is, a commitment to 'doing good' may be to err on the side of caution in instances where client autonomy may be in doubt. The participants described a meaning of 'autonomy' that was altered to suit the patient, so that care could be given to him without any infringement of that 'autonomy'. Lutzen et al (1994) refer to this process as 'modifying autonomy':

Modifying autonomy is defined as adjusting the meaning of self choice to suit the perceived needs of a patient when there is a conflict. In practice, this could entail enhancing as well as limiting the patient's self choice (p103)

In addition participants did not demonstrate commitment to a code of ethics that informed their practice. Lutzen et al (1994) suggest:

The nurses...did not seem to begin their point of moral reflection by referring to professional codes of ethics or to autonomy as an ethical principle. Rather it was the context of the nurse-patient relationship, involving choice and responsibility, rather than principles, that determined the nurses' definition of self choice. (p105)

The tension between autonomy and beneficence is addressed by Robertson (1996) who examined every day nursing and medical practice on a psychiatric inpatient unit. The data collected through participant observation was supplemented by interview with the participants.

Robertson identified that concern to act with beneficence and the need to respect the autonomy of the patient was "*the most salient pattern of ethical tension on the ward.*"(p296) However, it is interesting to note that in this study, nurses considered *all* patients to be autonomous and strove to enhance autonomy by promoting self-care wherever possible.

Ekman and Norberg (1988) interviewed 21 enrolled nurses and nursing aides in a clinic in Sweden. Participants were asked to describe the care of a patient they had recently looked after. The aim of the study was to determine whether problems of communication with patients with dementia contributed to a neglect of patient autonomy. In this study, autonomy was defined as "*the patient deciding for himself what to do*" and "*the care giver asking permission to do things*" (p184).

The researchers identified a tension between 'autonomy' and 'beneficence'. Again, as in the study conducted by Robertson (1996), all patients were assumed to be 'autonomous'. Nurses did not have a working definition of autonomy that informed their practice. This led to difficulties in identifying the person's wishes, which often appeared irrational.

In another study, Elander (1993) interviewed nurses who were working in long term care settings in Sweden and England in order to identify some of the ethical conflicts that commonly occurred in their daily work. The interviews were tape recorded and transcribed. The problem most frequently identified by participants was the divergent demands of patients and their relatives and the difficulty in reconciling the two. Many participants were unsure how to

respond to the different demands; they were not sure how much weight should be given to consideration of patient autonomy in the face of relative opposition. Elander et al (1993) concluded:

in trying to solve these conflicts, it is necessary to take into consideration not only the autonomy of patients but also of relatives. We suggest however that whenever possible, nurses should try to resolve the conflict by recognising that their loyalty should first and foremost be to their patient (p97)

This study identifies uncertainty among nurses as to whether patient autonomy should be respected when this conflicts with the demands of relatives. Given that respect for patient autonomy is a prerequisite for obtaining consent, failure to respect patient autonomy will clearly impede obtaining consent prior to nursing care procedures.

In a recent study, Holm (1997) interviewed nurses and doctors about their ethical approach to patient care. He concluded that health care professionals had a tendency to err towards considerations of beneficence rather than respect for patient autonomy; they tended to err on the side of caution when caring for vulnerable patients:

data showed that the health care professionals linked their personal responsibility to the vulnerable state of patients (p126)

Holm (1997) referred to this concept as 'protective responsibility' which he found came into play when a patient makes a decision that is not in his or her best medical or nursing interests:

if there is too large a discrepancy between what the patient wants and what is judged to be best for the patient, the latter may become the overriding consideration and unwanted paternalism may be the consequence (p157)

Holm (1997) described protective responsibility as an element of beneficence, but which is concerned only with protection from harm not the promotion of the general good. He described this limitation as a "*prudent adaptation to the real world*" (p156); a truly beneficent course of action being too difficult to apply.

Summary of studies of ethical reasoning

Studies of nurses' ethical reasoning provide some evidence concerning how nurses understand the concept of autonomy in clinical situations. Firstly, although nurses identify a tension between respect for patient autonomy and other competing interests, nurses tend to err on the side of beneficence. That is, nurses are concerned to carry out the care that they perceive to be in the patient's best interests rather than allow the patient to take responsibility for his care. There may be various reasons for this. Perhaps the system does not facilitate a different approach or there may be an emphasis on 'getting the work done' even if this means doing so against the wishes of the patient. In addition, some of the studies cited were undertaken in clinical areas, for example psychiatry and care of the elderly, where a patient's ability to make substantially autonomous choices might be reduced, (Beauchamp & Childress 1994). However, many nurses recognise a tension between beneficence and patient autonomy and are uneasy about the clinical path they tread.

Secondly, there is evidence that nurses are working with an undefined understanding of autonomy. This observation is explored in detail by the author in a separate paper, (Aveyard 2000). There is a tendency for all patients to be considered 'autonomous'. This understanding cannot form a working concept of autonomy, as clearly not all patients are autonomous enough to make their own decisions. While nurses can seek to enhance the limited autonomy of a patient in various ways, they must seek to protect those who are unable to make their own decisions.

All the studies described above contain data from real clinical situations; they recount incidents that took place as opposed to hypothetical actions suggested in response to a vignette or vague recollections and generalisations about clinical happenings. Reporting of actual incidents is often considered to provide a more authentic account of practice than general recollections, (Flanagan 1954). Interestingly, in a study in which clinicians' attitudes towards patient autonomy were discussed (without reference to specific clinical incidents), Woodward (1998) records how clinicians *reported* to respect patient autonomy over considerations of beneficence, which in her view is to the detriment of patient care. There may be some discrepancies between how nurses say they respect patient autonomy and what they actually do in practice. The following studies of nurses' ethical reasoning in relation to a patient who refuses food are not taken from real life care episodes, but are nurses' response to vignettes.

2.3.2 Studies of ethical reasoning in relation to food refusal

A series of studies examines nurses' ethical reasoning when a patient refuses food. Patient

autonomy and consent prior to nursing care procedures are therefore addressed directly in these studies.

Norberg et al (1988) interviewed 143 nursing aides and 48 enrolled nurses about food refusal among patients in 23 nursing homes. Using semi-structured interviews, the participants were asked to describe the care of a patient who had refused to eat.

The researchers identified a lack of discernment among staff as to whether the patient had refused food or merely did not have the ability to eat it. They comment:

it was evident from the accounts ...that almost no interviewees had such clear concepts of 'food refusal' that they would be able to differentiate between the lack of the wish to eat and the lack of ability to eat (p481)

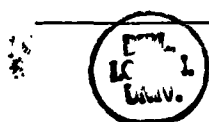
Care-givers did not distinguish between a patient's desire not to eat (refusal) and an inability to do so. Many patients experienced forced feeding. In addition, none of the participants suggested that the reasons for the food refusal should be investigated. The researchers indicate that the caregivers did not have the necessary skill to manage the care of a patient who refused to eat. They did not respect the autonomy of a patient who refused food, nor did they discern when the apparent refusal was really an inability to eat.

Importantly, this study focused on care given by unqualified staff. However, it is these staff who are often at the forefront of care. In the following studies, the ethical reasoning of qualified nurses when a patient refused food was addressed.

Jansson and Norberg (1989) interviewed 20 registered nurses who had been described as 'experienced and good' about the care of a mentally alert, terminally ill cancer patient who refused food. Participants were presented with a hypothetical situation, which they were asked to discuss.

All of the participants reported that they would respect the food refusal of the patient, but that they would continue to offer food. The authors describe:

they seemed to interpret the patient's refusal as the expression of a rational desire (p355)



There is no description or reason as to why the refusal was considered rational. Perhaps it was assumed due to the description of the patient as 'mentally alert'. Participants justified this reasoning by appeal to the principle of autonomy, but were unable to articulate why. They also said that guiding principles would depend on the situation in hand.

This study provides some evidence that qualified nurses are prepared to respect the autonomy of a patient who is mentally alert. However, that is not to say that respect for autonomy is given a higher moral value than principles of beneficence. Nurses in the study may have felt that to respect the terminally ill patient's refusal of food was also a beneficent act. It may be one thing to respect the autonomy of a patient who is terminally ill. It may be another to respect the autonomy of a patient who puts his health at risk but who does not have a limited life expectancy.

Taking an international perspective, Davidson et al (1990) carried out a similar study when they examined the ethical reasoning of 169 nurses in eight countries, who had been described as 'good and experienced'. Participants were asked to discuss the care of a mentally alert, terminally ill cancer patient.

With the exception of the participants from China and Israel, the results of this study were similar to those of the original study. The majority of nurses in Western countries reported that they would not feed the patient and justified this decision with appeal to the principle of autonomy. Again, there was no discussion as to whether the patient was actually 'autonomous'; perhaps this was assumed due to the description of the patient as 'mentally alert'. In contrast, all the nurses in China and 10/26 nurses in Israel said they would feed the patient, appealing to the principle of beneficence.

In a later study, Jansson et al (1995) presented the scenario of a patient who refused food to 20 nurses working with cancer patients and 20 nurses working with patients with dementia. All nurses had been described as 'good and experienced'. To the nurses working in cancer care, the patient in the scenario was described as 'mentally alert'. To the nurses working with patients with dementia, the patient in the scenario was described as 'severely demented'.

As in previous studies, all the cancer care nurses were prepared to accept the refusal of the terminally ill patient who refused food. They justified this by appeal to the principle of

autonomy. However, all nurses did not respect the patient with dementia's refusal. Some of the nurses were prepared to respect the patient's refusal of food, appealing again to a duty to respect the patient's autonomy. However other nurses interpreted the term autonomy in a different way. They did not feel that this patient was autonomous and were therefore willing to feed the patient against her 'wishes'.

Norberg et al (1994) interviewed 149 registered nurses in seven countries concerning the feeding of a patient with dementia who refused food. The participants were given a scenario of a patient who refused to eat.

45% nurses interviewed reported that they would respect the 'autonomy' of a patient with dementia who refused food. They justified this by appealing to the principles of beneficence and autonomy. Other nurses reported that they would not respect the refusal of the patient. They appealed to the principle of beneficence and the sanctity of life.

In another study, Day (1995) interviewed 40 cancer care and 40 dementia care nurses in four sites in America. Nurses included in the study had been described as 'expert' by their managers.

The case studies presented to the participants were similar to those used in the Swedish studies; a mentally alert terminally ill patient with cancer and an elderly lady with dementia. The patient with dementia has additional difficulties; she was described as incontinent, bedridden and not responsive to contact. The findings were similar to those of the Swedish studies. The majority of cancer nurses (95%) said they would not attempt to feed the patient. Again, they justified their decision by appealing to the patient's right to autonomy. The concept of autonomy was not defined, nor is it clear how the nurses made an assessment that the patient was able to make the decision. 5% of the cancer care nurses said that they would feed the patient, despite her (presumably autonomous) refusal. 27% of the dementia care nurses reported that they would not feed the patient. They justified this decision by appealing to the concept of autonomy.

There are two points that should be made here about the series of studies concerning the patient who refuses food. Firstly, there seems to be an implicit agreement among the nurses that if a patient is autonomous, her refusal should be respected. Secondly, however, autonomy did not have the same meaning for all nurses. This is important as it affected the nurses' approach to patient care. Some nurses employed a liberal notion of autonomy whereby all patients,

irrespective of their ability to make decisions were considered 'autonomous'. Any nursing care carried out against their wishes was considered to be a breach of 'autonomy'. These nurses were prepared to respect the refusal of food made by the patient with dementia even though the patient may not have understood what she was refusing. Other nurses did not consider all patients to be autonomous. They made an assessment, although it is not clear how, as to whether the decision of a patient reflected her autonomous choice and therefore whether it should be respected.

In a further study incorporating a different methodology from the studies cited above, Mattiasson and Andersson (1994) examined nursing care of patients who refuse to eat and drink through the use of a self report questionnaire, administered to 189 health care professionals in 13 nursing homes in Sweden. Participants were asked to consider the scenario of a competent elderly resident who refuses to eat and drink. In this study, the scenario is lengthier, and incorporates the views of the patient's brother. Unlike the previous three papers, there was no intention to select 'good and experienced' staff.

The results of the study are also different. In this study, only 50% of the participants felt that the patient's wishes should be respected. Furthermore only 25% of the participants felt that, in practice, the wishes of the patient would be respected.

The results of the study do not demonstrate a commitment to the right of a patient to refuse food. The researchers suggest that staff reluctance to respect the patient's decision was a reflection of their experience, qualifications and institutional factors. They suggest:

higher level of education and longer experience of work in medical care tend to be accompanied by a greater acknowledgement of the patient's wishes (p827)

In a later study, Mattiasson and Andersson (1995) examined the views of 189 professional care givers in 13 nursing homes in Sweden. The participants were invited to comment upon six scenarios in a self report questionnaire. Two scenarios concerned a refusal of life sustaining treatment and whether this should be upheld.

Most qualified staff agreed that if a patient's decision was considered to be authentic, it should be respected. However, the components of an 'authentic' decision were not identified. Unqualified staff were reluctant to respect the decision of a patient who refused treatment

irrespective of whether this was considered to be the 'authentic' decision of the patient.

Discussion of studies of ethical reasoning in relation to food refusal

Several points can be made about this series of studies.

Firstly, there is evidence that an experienced nurse in a western culture may respect the refusal of food by a mentally alert, terminally ill patient. However, this is an assertion made in response to a vignette and there is no evidence that it would be implemented in a clinical situation. Even so, most nurses report that they would respect the refusal of food. However, it cannot be assumed that respect for patient autonomy was the nurses' only concern. It could be that respect for patient autonomy in this instance was consistent with the nurses' perception of beneficence; that to refuse food, and so hasten death was indeed in the patients' best interests. When the nurse is less experienced, or the patient is not in a western culture, there is less chance that the refusal will be respected.

Secondly, some nurses reported that they would respect the refusal of a patient who was suffering from dementia. However, not all experienced nurses reported that they would respect the refusal of a patient suffering from dementia. Importantly, there was no consensus as to whether the patient with dementia was autonomous. As in the studies cited in Section 2.3.1, autonomy did not have the same meaning for all nurses and this affected the nurses' approach to patient care.

These studies raise many questions. It is unclear on what basis the participants are making a judgement. There is some evidence that nurses are aware that patient autonomy, which is demonstrated in these examples by the refusal of food, should be respected. However, in these examples, the patient specifically demonstrated her refusal of food. This demanded a response from the nurse. They do not provide any evidence as to how nurses actively seek consent.

2.3.3 Summary of studies of nurses' ethical reasoning

When nurses are asked to identify and discuss real life situations (Section 2.3.1), there is evidence of a tension between considerations of patient autonomy and beneficence. Nurses demonstrate a tendency to err towards beneficence, a reasoning described by Holm (1997) as 'protective responsibility'.

In a series of studies in which nurses are asked to respond to vignettes about a patient who refuses food (Section 2.3.2), the tension between autonomy and beneficence is less apparent.

Many nurses are prepared to respect the autonomy of a patient who refuses food. However these were not real life incidents, but responses to vignettes. They do not provide evidence about real life care.

Common to both sets of study is a lack of a clear definition of the meaning of patient autonomy. There is no evidence that nurses are working with a clearly defined understanding of autonomy that informed their practice. This is important as without this, it is not possible to determine when a patient has given her autonomous authorisation to the proposed procedure.

2.4 Studies of informed consent in nursing

There is a scarcity of information concerning how informed consent is obtained from patients prior to nursing care procedures. However, examination of empirical studies concerning nurses' involvement in and perception of the informed consent process prior to medical and research procedures provides some evidence as to the extent to which nurses understand the principles associated with informed consent and their attitudes towards it.

In addition to empirical studies, non-empirical work undertaken by nurse theorists and clinicians is included in this chapter. This work provides a useful barometer of attitude towards informed consent within the nursing profession.

2.4.1 Studies of informed consent prior to medical procedures

The largest body of nursing literature focuses on the nurses' role in facilitating the patient's consent to medical procedures. Five studies were identified in which the nurses' role in the informed consent process prior to medical procedures is examined and the majority of discussion within the nursing literature concerning consent focuses on this issue.

Empirical studies

In the first study, Whalen (1984) examined the attitudes of nurses regarding the informed consent process prior to the insertion and maintenance of a pulmonary artery catheter. In a questionnaire survey of 52 nurses, participants were asked to rank the importance of various aspects of consent. Two observations are interesting. First, 90% respondents rated the patient's right to refuse the procedure as the most important. Second, respondents consistently rated the disclosure of risks as less important than the disclosure of benefits. Thus while a patient's refusal was considered important and should be respected, participants were not always prepared to emphasise the potential risks the procedure entailed. However, the author found

that nurses attached considerable importance to the disclosure of potential discomfort to be anticipated during the course of the procedure. She emphasised that nurses should take responsibility for these aspects of obtaining the patient's consent. She suggests:

it would be logical to maintain that procedural aspects for which nursing has primary accountability should also be explained by a nurse (p665)

This reference of the importance of consent for care procedures for which the nurse has direct responsibility is an initial acknowledgement of the importance of consent prior to nursing care procedures.

In a later study, Carney (1987) interviewed 16 qualified nurses and 5 physicians in order to examine the role of the nurse in facilitating the informed consent process prior to bone marrow transplantation. She found that nurses perceived that they should have a greater role in the informed consent process than the role perceived for them by physicians. In addition, nurses advocated a greater amount of disclosure to the patient regarding the procedure than did physicians, who preferred to tell the patient what he 'needed to know' rather than all the available facts.

Davis (1988) discussed vignettes with 27 qualified nurses in order to investigate their knowledge, experience and perception of the informed consent process. The vignettes related to consent prior to medical or research procedures. Davis identified that nurses perceived informed consent as a process, ideally occurring over a period of time. They identified various ways in which this process could be enhanced, including clear communication with the patient. However, participants identified that patients were sometimes guided towards a treatment option; that is, although they were given the available options, they received a covert message that they should select a particular option. Davis identified that participants did not perceive the system to be patient oriented and that free choice was rarely possible. In addition, participants identified that pressure of time, adherence to ward routines, and high turnover of staff did not facilitate the informed consent process. Davis identified that nurses perceived themselves as watchdog, advocate, resource person, co-ordinator and facilitator.

Kee (1995) examined nurses' knowledge of and contribution to the informed consent process (prior to medical procedures) in a questionnaire study. The questionnaire focused on participants' knowledge of consent and their perception of the nurse's role in facilitating

consent prior to non-nursing procedures; for example, whether the nurse should be present during physician-patient consent procedures and how this should be documented. Nurses identified their role in the (medical) consent procedure as ensuring that the patient has understood the procedure.

Costa-D'sa (1996) carried out semi-structured interviews with 21 nurses in order to explore their understanding of the informed consent process. During the interview, participants were presented with 5 vignettes; each vignette concerned an element of informed consent theory (information giving, competence and non-coercion). All vignettes focused on consent for medical procedures. Analysis of data indicated that, with the exception of the competence component of consent, many nurses were able to recognise the elements of informed consent theory. However, whether recognition of these elements from case vignettes would be translated into clinical practice could not be determined by the study.

These five studies give some indication that the participants involved had some understanding of the informed consent process, although they do not give any detail as to the extent of this understanding. Furthermore, the studies obtain a hypothetical account of nurses' attitudes to informed consent; which may not reflect what nurses actually do. This is especially interesting in relation to the observation made by Whalen (1984), that 90% participants felt the right to refuse to be the most significant aspect of consent. The data obtained for this study indicates that nurses do not respect this right in practice. This will be demonstrated later. Finally, all studies focus on the nurses' role in facilitating consent prior to non-nursing procedures and emphasise the bias in the nursing literature on this area of concern.

Supporting nursing literature.

The vast majority of writing about consent in the nursing literature focuses on the significance of consent prior to medical procedures, for example Parker (1999). Nurse theorists and clinicians who write about informed consent prior to medical procedures prescribe the role of the nurse as essentially supportive to the physician-patient interaction; nurses should clarify misunderstandings but not become involved in the process, (Cisar 1995), (Erlen 1994), (Yorker 1989), (Cunningham 1989) and Kennett (1986). (1986) argues:

the nurses' role as intermediary requires knowledge and a commitment to this concept of assisting patients in making an intelligent, educated decision; that is in ensuring patient autonomy (p77)

The role of the nurse in facilitating patient's consent prior to medical, surgical or research procedures is undoubtedly important, (Mitchell 1994). Some authors suggest that the nurse should take increasing responsibility in the informed consent process for medical procedures, (Tait 1989). However, a note of caution regarding the role of the nurse in obtaining consent for medical procedures is offered by Tingle (1990) and Hollowell & Eldridge (1989). They warn of the dangers of nurses taking on what is essentially the role of the doctor in the consent process for medical (i.e. non-nursing) procedures.

Nurses who do the job of a doctor regarding patient consent should be aware that they are entering a very grey legal area. (Tingle 1990 p52)

Clearly, if nurses become more involved in the consent process prior to medical procedures, they must be competent to do so. There has been recent concern about the standard of consent obtained by junior doctors. Richardson et al (1996) observed that 80% respondents to a questionnaire failed to answer simple questions regarding legal aspects of consent, and that 62% had obtained 'consent' from patients to operations on several occasions that they themselves did not understand.

The extent to which the nurse should become involved in the informed consent process prior to medical procedures is not the focus of this thesis. It is interesting that the majority of the literature focuses on this subject. It may be implied that the common view of informed consent within nursing is associated with consent prior to medical procedures.

The studies that have been carried out focus on nurses' views on and their response to hypothetical vignettes about consent prior to medical procedures. However studies are small, few in number, and given the changing attitudes towards consent in recent years, largely outdated. The evidence provided in the studies does not give any strong indication of nurses' approach to the application of the principles of consent. Also, there is no evidence about what nurses do.

2.4.2 Studies of informed consent prior to patient participation in medical research.

Empirical studies

Davis (1989) carried out semi-structured interviews with 27 nurses who were involved in clinical research. Participants were asked about the difficulties associated with informed

consent in research protocols. Davis identified an uncertainty about the nursing role in obtaining consent prior to clinical research, difficulties in the relationship between the nurse and the researcher, and uncertainty whether the patient was willing to enter the study. Staff interviewed described their role in the consent process as 'undefined' - which led to confusion as to their ethical obligation to the patient.

In a later study Nusbaum & Chenitz (1990) investigated the formal consent interview between researcher and patient. The researchers observed sixteen interviews with researchers (some of whom were nurses) and patients. Following the observed 'consent interview', the clinicians involved were interviewed by the researcher. They demonstrated concern as to the quality of the 'consent' obtained and identified that the focus of the interview was to enrol the patient into the trial, not to seek his consent to do so. The researchers concluded that there was a:

poor fit between the elements of informed consent (disclosure, comprehension, voluntariness and competence) and the interaction during formal consent interviews.
(p226)

Supporting nursing literature

Nurse theorists and clinicians discuss the role of the nurse in obtaining consent prior to medical research in largely the same way as for consent prior to medical procedures. . Rempusheski (1991) and Alderson (1995) emphasise the nurses' role in supporting the decision of the patient whether or not to enter the trial and the importance of clear information. Chamorro and Appelbaum (1988) suggests that to regard consent as the sole domain of the physician is a misconception, given that nurses frequently take responsibility for various aspects of treatment, for which they should ensure that consent is sought. The 'watchdog' role identified by Davis (1988) is clearly significant. The patient has a right to withdraw his or her consent to participate at any time. If the nurse is involved in the research process he or she should be mindful of this and facilitate a patient's withdrawal should the need arise.

2.4.3 Studies of informed consent prior to participation in nursing research.

Empirical studies

Duffy et al (1989) sought consent from 83 elderly patients for a non invasive, comprehensive assessment. 50 patients gave their consent to participate in the study assessment. They identified that the opinions of significant others played a crucial role in the elderly patient's decision to participate but that those who ultimately decide to participate in a study took longer

to reach the decision than those who did not participate. She concluded that elderly patients are capable of weighing the risk-benefits of a proposed intervention and that the difficulties involved in obtaining consent from an elderly population should not preclude their invitation to participate in research.

Supporting nursing literature

Oberst (1985) examines the difficulties of obtaining consent from patients participating in nursing and medical research but states that:

we cannot be relieved of our ethical obligation simply because the process is difficult or imperfect (p294).

She discusses the importance of inviting appropriate patients to participate and of the importance of good communication. Alt-White (1995) suggest that some elderly patients may participate in studies to please those involved. The specific difficulties relating to consent and research in an elderly population are described by Robb (1983) who emphasises that despite the problems likely to be encountered, consent must be a central concern when undertaking research with patients.

2.4.4 Studies of informed consent prior to nursing care procedures

Empirical studies

No studies were identified which examined informed consent prior to nursing care procedures. This absence is also illustrated in an annotated bibliography of empirical research on informed consent, (Sugarman et al. 1999). However two empirical studies were identified which examined information given to patients and their role in determining the course of clinical events. McCormack (1998) undertook a doctoral thesis in which he examined the ways in which nurses respected the autonomy of elderly patients in the process of planning discharge from hospital. Recording naturally occurring conversations between patients and nurses, McCormack was able to identify the ways in which nurse patient interaction may facilitate or inhibit patient choice and involvement in the discharge process. Although the focus of this research was on respect for autonomy rather than informed consent, the two concepts are clearly interwoven. Information giving and the patient's freedom to choose are associated both with patient autonomy and with informed consent, the aim of which is to protect patient autonomy. McCormack found that professional power, institutional constraints often restrained

patient choice, despite finding that information giving played a dominant role in patient care. With reference to information giving, for example, McCormack notes that:

the lack of a clear framework in which such information was contained and the dominant role of professionals in decision making resulted in such information acting as another form of control that served to reinforce the decisions already made by professionals, rather than as a means of enabling decision making by patients themselves (p300)

In another study, Levy (1999b) studied the communication between women and their midwives in a grounded theory study of informed choices during childbirth. Observation and interviews were used to examine the choices given to women. Levy identified the core concept of 'protective steering' which is employed by midwives when discussing care options with women. She found that midwives described a culture of 'walking a tightrope' when informing women of choices while wishing to direct their choice towards a preferred course of action.

The study by Levy (1999a) provides evidence to indicate that women were guided in their choices about care in childbirth. Whether the midwives were working with a philosophy of shared decision making or overt beneficence will depend on the 'severity' of this guiding and the extent to which information about possible choices was withheld or possibly misrepresented to women. She described:

midwives acted as gatekeepers of information, controlling its release in order to achieve a balance of providing enough information to permit what they regarded as safe information choices to be made while avoiding excessive information that might frighten or confuse the woman (p615)

Clearly there is a balance to be struck here. On the one side, patients need help with their decision making. The term shared decision making as discussed in Chapter 1 incorporates this view. On the other side, this help should not be such that it merely facilitates patient compliance with pre-made professional decisions, as observed in McCormack's study (1998), discussed in more detail in Chapters 4&5. However, the consequences of failing to guide patient decision making are addressed by Levy (1999b). She describes:

if the right line was not picked, highly undesirable outcomes could result. For example,

the woman could be frightened, or feel patronised, colleagues could be upset, unrealistic expectations could be encouraged and the woman's safety (and the midwife's) wellbeing and safety compromised. Protective steering was thus a fundamental as well as a highly complex activity which required considerable personal sensitivity together with professional skill and knowledge (p106)

The value of the studies by McCormack (1998), Levy (1999a) and Levy (1999b) is that they provide an account of observed practice, rather than the hypothetical responses to vignettes. Both studies give a clear indication that patient choice is constrained within the health care system. Both studies acknowledge the difficulty of striking the right balance so as to promote patient choice *in so far as it is wanted by the patient* and thereby not to infringe his or her autonomy, as discussed in Chapter 1. However, there is evidence that this balance is frequently weighted towards limiting patient choice so as to ensure that the course of action planned for the patient can take place. Aware of the potential for patients to refuse care, nurses employ strategies to promote compliance.

These two studies focus on nursing practice in a particular care situation; discharge planning and childbirth. The authors did not examine the wider context of consent prior to nursing care procedures. However, they indicate how information is used to promote patient compliance with the care that is perceived to be beneficial. The extent to which this approach is utilised by participants in the present study in their facilitation of consent prior to nursing care procedures will be examined further in this thesis.

Supporting nursing literature

The way in which consent is discussed in the nursing literature and text books will be briefly reviewed.

Much of the discussion about consent in the nursing literature does not mention consent prior to nursing care procedures. The majority of the discussion about informed consent in the nursing literature focuses on the nurses' role in obtaining consent prior to medical procedures or research. This is indicative of the lack of acknowledgement or discussion about the relevance of consent prior to nursing care procedures. For example, Buchanan (1995) discusses the legal framework in which consent is embedded and how the patient's ability to consent is dependent on adequate communication. The interesting point in Buchanan's article lies, perhaps, in its scope and focus. Consent is discussed in terms of medical or surgical procedures. The article

commences as follows:

Before surgery or invasive treatment doctors are legally required to obtain the consent of their patients. (p27)

No reference is made to consent that may be required for nursing care and procedures. In addition, a selection of nursing ethics text books were reviewed in order to examine how the concept of consent prior to nursing care is addressed. Consent prior to nursing care procedures is not mentioned at all in some of the text books reviewed, (Benjamin & Curtis 1992), (Rowson 1990), (Hustead & Hustead 1991), (Rumbold 1993), (Chadwick & Todd 1992).

However, most of the text books which mentioned informed consent prior to nursing care procedures expressed commitment to consent prior to nursing care procedures, although some suggested that the requirement to obtain consent may have a negative effect on the nurse-patient relationship, (Melia 1989), (Tschudin 1992), (Fletcher, N. et al. 1995), (Fowler & Levine-Aviff 1987) and (Johnstone 1994) who argues:

Nurses need to pay much greater attention to the doctrine of informed consent...not least the duty it imposes ..to obtain patients' informed consent to nursing care and procedures.....nurses are no less exempt than are any other health care professionals from the moral standards governing consent procedures (p250)

Informed consent prior to nursing care procedures is not addressed in many nursing texts and references. In addition, the concept of autonomy is interpreted in a variety of ways. Oddi (1994) discusses patient autonomy. While she acknowledges the significance of patient autonomy and the role of informed consent in its protection, she does not regard either as essential features of the nurse-patient relationship. In her view, considerations of beneficence should override those of autonomy (and presumably therefore consent should not be sought) in the following situations:

*the risks associated with the action are not substantial...
the projected benefits of the action to the patient outweigh any risks (p62)*

This second example must apply to all nursing care procedures. Is she thereby saying that consent is not important in the nurse-patient relationship?

Echoing these sentiments, Benjamin and Curtis (1992) suggest that paternalistic actions are justifiable if the patient is likely to be significantly harmed if the intervention is not carried out. Davis & Underwood (1989) suggest that a nursing care procedure is justifiable if it is aimed at restoring the self care of the patient, presumably, even if the patient objects:

the nurse should engage in those actions which have the greatest likelihood of restoring, maintaining or increasing the self care agency so that the patient can assume responsibility for his own health related self care (p276)

Similarly, Brown (1995) does not regard informed consent as a requirement prior to nursing care procedures:

in a health care setting, the practitioner has to weigh society's and the organisation's right to coerce against the individual's right to freedom and autonomy (p60)

and

It can be considered a mistake to assume that autonomy interests should always take precedence over interest in pleasant experiences. It may be better to compromise a patient's autonomy in order to prevent him or her suffering pain. This view raises questions about how to calculate trade offs between losses of autonomy and gains in pleasure. (p61)

Finally, Woodward (1998) perceives a trend over which she expresses concern; that principles of autonomy should dominate the current approach to patient care. She carried out a non-participant observation and semi-structured interview study in two clinical settings. Participants interviewed in this study expressed a strong commitment to principles of autonomy; although there is no evidence that this would reflect their preferred approach in real life situations. However Woodward is critical of this potential commitment to patient autonomy:

it is argued that beneficent intervention should not be uncritically superseded by the contemporary emphasis on autonomy. This disregards the intrinsic morality in a caring relationship, deprives the patient of the qualitative component of care and personalised application of knowledge and skills, threatens to diminish the source of professional motivation and may result in self reproach and retribution through

frustrated moral agency (p1051)

It has been argued in Chapter 1 that patient autonomy and practitioner beneficence are intrinsically linked. Such analysis might ease Woodward's concern that acknowledgement of patient autonomy does not relinquish the practitioner from the duty to care for the patient.

However, some nurse theorists and clinicians are committed to the concept of consent prior to nursing care procedures. Kendrick (1994) argues that consent is required for nursing care procedures:

Consent does not just concern the treatments doctors offer patients; nurses are also involved in a host of interventions which demand patients' permission... It may seem obvious that we gain consent prior to a catheterisation or injection, but what about before a bed bath or even before taking a temperature? Do we require informed consent prior to taking a patient's blood pressure? Where should we draw the line? Would consent be necessary for all or just a few of these nursing actions? (p739)

Unfortunately, Kendrick does not address any of these questions in the content of the article that follows. Instead, he discusses the care of a patient who is unable to consent to any care or procedures and the difficulties experienced. His final comment indicates a commitment to, although he does not say how this should be achieved, integrating principles of informed consent into every day nursing practice.

The freedom to choose a course of action, in conjunction with a nurse facilitating this choice, is an excellent testimony to the power and position which informed consent must enjoy in all of our professional lives (p742)

Hewetson (1994) also argues that consent should be obtained for all care procedures:

whether that person is taking blood, or doing a dressing, or administering medication.. and adds (remember that consent may be implied) (p15)

Commitment to the concept of obtaining informed consent prior to nursing care procedures is given by Tschudin (1989) who warns that information giving is not the same as consent seeking. Cook (1992) also advocates consent prior to nursing care procedures, but suggests that

a potential problem may be that many risks involved have not been quantified, thus limiting the possibility for making an informed choice. He suggests that nurses should rectify this (p44).

One aspect of consent prior to nursing care procedures that is discussed in the nursing literature is how consent should be facilitated. Brennan (1997) advocates that consent should be an integral part of care (p481) and that this will be facilitated by a trusting relationship and good communication. (p482).

Calder (1989) supports Brennan's view that consent should be an integral component of care. She writes:

nurses obtain verbal or implied consent from patients before routine, daily nursing procedures such as medication administration and dressing changes. Nurses are accustomed to developing the co-operative partnership recommended when seeking informed consent (p25)

Plank (1994) explores a possible process whereby informed consent may be facilitated in nursing. She examines the usefulness of a process she describes as 'framing treatment options'. This is a process whereby treatment options are explored in detail with the patient. Although the focus of the article is on the role of the nurse in facilitating the patient to reach decisions about medical treatment, she does discuss the use of framing treatment options in promoting patient involvement in daily nursing care activities.

Usher and Arthur (1998) propose that consent is an on-going consensual process involving the nurse and patient in mutual decision making, ensuring that the patient is kept informed at all stages of care:

informed consent...is seen as a process that must be agreed to and negotiated at each step of the treatment process. (p696)

There is some discussion about the use of written consent forms for obtaining consent prior to nursing care procedures, (Wicker 1991), (Cook, A. 1992). Cook comments on the model consent form supplied by the NHS Management Executive. He states his belief:

that nurses will not recognise it (p46)

He reports the reaction of some members of staff within his health authority to the concept of consent forms and states that 90% greeted the idea with "*surprise at best, disbelief and horror at worst*" (p46). In a second article, refers again to the guidelines issued by the NHS Management Executive (1990). He states that the procedures for which written consent will be required are unknown.

Cook (1992) and Wicker (1991) observe that nurses must understand the ethical and legal principles of consent for nursing care. This must be seen as crucial. Unless nurses are adequately informed about the principles of consent they will be unable to apply the principles to nursing practice or to inform and move forward with the debate as to the appropriateness of written consent for nursing care.

Specific reference is given to consent in view of considerations of nurses' extending their role to undertake additional procedures, (Power 1997). Scholefield et al (1997) assert that "*some areas of practice involve the need to obtain informed consent*" (p12.) They document a policy, emphasising the acquisition of skills and knowledge for the development of nursing practice in line with SCOPE guidelines developed at the Queen's Medical Centre, Nottingham.

Intrinsically associated with the concept of informed consent is the concept of patient refusal. Patient refusal is addressed in the nursing literature, (Hunka 1993), (Murphy 1993), (Robson 1994), (Taylor 1995), (Longo 1993) and (McGrath 1995). In these articles, the right of a patient to refuse any aspect of care is acknowledged.

The role of consent prior to nursing care procedures is ignored by some nurse ethicists and accepted by others. Some writers appear to acknowledge the concept of consent but do not show any commitment to it. Others are sceptical. There is no clear uniform approach to discussion of consent prior to nursing care procedures. There is evidence that the concept has not been fully explored .

Discussion of studies of nurses' understanding of the informed consent process

There is no direct evidence in the nursing literature concerning how nurses obtain consent from patients prior to nursing care procedures. The vast majority of the literature focuses on the nurses' role in facilitating consent prior to research or medical and surgical procedures. When informed consent prior to nursing care procedures is addressed, most writers claim to support

the concept in nursing, although this is not universally endorsed. With specific reference to nursing care procedures, two studies indicate that nurses direct clinical conversations about patient choice to their preferred ends; thus minimising any real choice the patient may have. While it is unrealistic and unhelpful for a practitioner to retain a neutral stance when suggesting care options, a middle ground might most usefully be pursued. These studies indicate that there is a strong tendency for practitioners to focus on their (perceived) beneficent duties when caring for patients at the expense of facilitating patient choice.

2.5 Summary of literature review

An extensive review of the nursing and supporting literature identified no empirical evidence concerning how nurses obtain consent prior to nursing care procedures. There was also very little discussion of consent prior to nursing care procedures. Instead, discussion focused on the nurses' role in facilitating consent prior to non-nursing procedures.

In Chapter 1, the significance of the principles of informed consent prior to nursing care procedures was established. Given this significance, it is remarkable to note that the topic has received little attention in nursing research or peer discussion, as identifiable in the literature.

This lack of research and discussion is important in two ways.

Firstly, it identifies a knowledge gap, concerning the way in which consent prior to nursing care procedures is addressed. Consent prior to nursing care procedures is an important area about which little is known. This study seeks to address this.

Secondly, it is likely that the absence of discussion and empirical studies concerning informed consent prior to nursing care procedures is indicative of its present status within nursing theory and practice. That is, consent prior to nursing care might not be discussed because it is not considered to be important. Furthermore, studies that demonstrate that nurses have a tendency to adopt a heavily 'protective' approach to their patients without facilitating patient choice, add weight to the suggestion that consent is not high on nurses' caring agenda.

This literature review is therefore helpful in validating the aims of the present thesis. The first aim of the study is to examine how consent is obtained prior to nursing care procedures. No similar work has been identified in this area. The second aim of the study is to explore how consent could be approached by clinical nurses. There is minimal discussion of consent prior to nursing care procedures in the nursing literature. This suggests that the concept of consent prior to nursing care

procedures is an undeveloped concept.

3 CHAPTER 3: METHODS OF INQUIRY

3.1 Philosophical background to the study

3.1.1 Introduction

It has been argued that the principles of informed consent are applicable to those nursing care procedures, which threaten the autonomy of the patient. Furthermore, it has been argued that these care procedures cannot be predefined – what is significant for one patient may not be significant for another. Instead, a preferred approach is that the nurse who is looking after the patient should identify those procedures to which an individual's consent is required. Clearly, this requires an understanding of the informed consent process rather than an adherence to a set of rules.

Review of the empirical nursing literature did not identify any studies that illustrate how consent prior to nursing care procedures is obtained. Furthermore, there is little discussion of consent prior to nursing care procedures, indicating that the concept remains largely unaddressed within nursing. Two implications can be drawn from these findings. Firstly, that there is little evidence concerning how consent is obtained prior to nursing care procedures. Secondly, furthermore, that this lack of attention given to consent prior to nursing care procedures in the literature reflects a lack of attention given to consent prior to the care procedures in clinical situations.

The aims of this research are to explore how consent prior to nursing care procedures is addressed by nurses in clinical practice and to develop discussion concerning how consent could be approached by nurses. An understanding and awareness of the problems inherent in the process of obtaining consent as implemented and perceived by nurses is necessary to identify principles derived from informed consent theory that might usefully guide nursing practice. Analysis of current practice is required before principles for good practice can be established.

The research questions to be addressed in this thesis can be defined as follows.

- a) How is consent prior to nursing care procedures obtained by nurses in every day clinical practice? Specifically, do nurses recognise that consent is required prior to certain nursing care procedures and do they implement the principles of informed consent in an appropriate format in such instances?

b) How could consent be approached by nurses prior to nursing care procedures?

3.1.2 The author's perspective on the study topic

It is important to comment on the perspective of the author on the study topic. It should be acknowledged that the author approached the study with a presumption in favour of the concept of consent and its application prior to nursing care procedures. This will be evident from the ways in which the arguments concerning consent are presented in Chapter 1. This predisposition towards the importance of consent can be partly attributed to the educational experiences of the author. Previous completion of a masters course in Medical Law and Ethics at an educational establishment whose main concern and research interests at the time focused on the importance of patient rights. Consent prior to nursing care procedures clearly falls into this remit, although interestingly this topic was never discussed formally in the course. However the interest of the author was captured throughout this period of study. On completion of the course, using the legal and ethical arguments to inform her nursing practice, the author explored possibilities for developing the concept of consent prior to nursing care procedures in a research study. This possibility materialised when the author was awarded the Morva Fordham Scholarship in Health Care Ethics. The scholarship was awarded by the Society for the Furtherance of Critical Philosophy. Significantly, Morva Fordham had been a lecturer throughout the author's undergraduate studies at King's College.

Although the author's predisposition towards the concept of consent prior to nursing care procedures is acknowledged throughout this thesis, it is significant to note that the author's perception and understanding of the process has progressed and altered throughout the study. The process of data collection and reflection on the concept of consent prior to nursing care formed and reformed the author's perception. These new insights into the way in which consent can be considered prior to nursing care procedures are developed in Chapter 7.

3.1.3 Summary of data collection methods used in this study

In order to address these questions, a rich description of nursing practice focusing on how nurses obtain consent prior to nursing care procedures was required. This description of care should include an account or observation of how consent is obtained in addition to nurses' interpretation of why consent is obtained as described. In view of this, focus groups and critical incidents collected through in-depth interviews were selected as data collection methods for this study in order to obtain nurses' accounts of how they obtain consent prior to nursing care procedures.

Focus groups were selected as a means of generating some background exploratory data concerning how consent is addressed by nurses in clinical practice. Discussion in the focus groups focused on how consent is obtained prior to nursing care procedures. The aim of the discussions generated by the focus group interviews was to generate background data in order to set a context for subsequent data collection. All focus groups were moderated by the author.

Critical incidents, collected through in-depth interviews were selected as a means of focusing on specific incidents in clinical practice in more depth. Participants were asked to identify incidents in practice concerning consent prior to nursing care procedures. Critical incidents were used as a method of observation and vehicle for discussing practice reported. All critical incident interviews were conducted by the author.

The purpose of these two methods of data collection was to provide an insight into the ways in which nurses approach consent prior to nursing care procedures, examining practice from both general and specific contexts. The process of identifying and selecting these two methods of data collection is given in the following section.

3.1.4 Identification of a research philosophy to guide data collection and analysis.

In order to obtain a description of nursing practice, commitment to a research philosophy was required that would guide the development of data collection and analysis. The question became, how should a rich description of practice be obtained?

Positivist approaches, requiring the observer “*to stand behind a thick wall of one way glass*” in a quest for objectivity and a value free framework, (Guba 1990) (p19) were considered inappropriate for addressing these questions. It was considered that a rich description of practice would not be achieved by objective observation alone without the interpretation and discussion of practice observed. Consent is an interaction that may not be easily measurable or observable. As an interaction, it may not occur as a discrete event, but rather may take place over time and may be intertwined within the context of the nurse patient relationship. For these reasons, observation of practice alone would be likely to fail to capture the essence of nursing practice. Observed events would be open to misinterpretation and events remaining unobserved might leave large holes in the data collected. It was likewise considered that a questionnaire or structured interview would also be unlikely to capture the essence of the complex interactional processes associated with obtaining consent in a clinical setting. Thus, a positivist approach, emphasising objectivity and a quest for true meaning, would be likely, on this occasion to

facilitate neither.

Post-positivist approaches focusing on attempts to produce objective 'positivist style' accounts were similarly rejected. It was considered that any account of the way in which informed consent is obtained prior to nursing care procedures would rely on the interpretation of that account. A purely objective account would be likely to fail to capture the essence of practice.

Instead, an approach that facilitated the detailed examination of a subtle but complex nursing practice of obtaining consent was required. The approach should emphasise the importance of interaction between inquirer and inquiree as a means of eliciting insight into the process of obtaining consent; insight which might not be apparent without this in depth interaction. In view of this, a constructivist paradigm was selected as an appropriate research philosophy that would guide the data collection and analysis for this thesis.

Constructivists do not demand that inquiry be objective and value free. For constructivists, the results of an inquiry are always shaped by the interaction of the inquirer and inquired into; the findings of an inquiry are '*the residue of a process that literally creates them*', (Guba 1990) (p26). Reality is constructed by those who participate in the research study and may be developed and refined as a process of involvement in the study. In view of this, many constructions are possible. Constructivist accounts of practice will necessarily be value laden social reconstructions of practice. They will necessarily be subjective.

Guba (1990) argues that constructivism is an entirely new paradigm, in which relativism and subjectivity replace objectivity:

Relativism is the key to openness and the continuing search for ever more informed and sophisticated constructions...subjectivity is not only forced onto us by the human condition...but because it is the only means of unlocking the constructions held by individuals (p26)

Constructivist inquiry was considered to be an appropriate research paradigm to guide the collection and analysis of data for this thesis. Discussion and examination of that practice is required to uncover the meaning and significance of observed practice. The meaning and significance might be unclear not only to the detached observer but also to those involved in the practice of obtaining consent. Through the use of discussion in the research setting, the

realities and perceptions initially presented by those participating in the study can be challenged and reconstructed. Discussion can be used as a tool to clarify and enhance meaning as described by Barnes (1976).

In constructivist inquiry, realities are constructed by those involved in the study. It is therefore suggested that while the approach is necessarily subjective, it may lead to insights that are a closer account of 'reality' than those obtained by alternative approaches. It is therefore suggested that the application of this paradigm might ultimately lead to a description of nursing care that is a closer reflection of the reality of practice than might be obtained by the application of alternative 'positivist' paradigms.

3.2 Focus group discussion to explore how consent is obtained prior to nursing care procedures

3.2.1 The use of focus groups in this study.

Focus groups were selected as a means of generating some background exploratory data concerning how consent is addressed by nurses in clinical practice. The practice of gaining consent prior to nursing care procedures is a potentially complex activity, which may be influenced by the ward environment, the nurses' perception of the patients' wishes, perception of the significance of consent to nursing care procedures and so on. Furthermore, early discussion with colleagues prior to commencing this study indicated that the concept of consent to nursing care procedures may not be one that is familiar to nurses; an observation that was also borne out in the literature review (Chapter 2). Indeed, when the focus of the study was introduced to potential participants, the following comment was typical:

"I'd never thought about consent to nursing care". (Interview 27)

It was therefore anticipated that some exploratory focus group interviews would be useful in generating discussion about the way in which consent is gained prior to nursing care procedures. It was anticipated that these discussions would achieve insights, which would not be attained in a one-to-one interview.

The social constructions created through focus group research are different from those created in one to one interviews. However, that is not to say that one or other construction is more useful for examining how consent is obtained prior to nursing care procedures. The aim of focus group study in this thesis was to achieve group discussion about the way in which

consent is obtained and participants' views as to why consent is gained in the manner portrayed. Most valuably, the discussion would be generated by the group participants rather than by the facilitator.

Clearly, the appropriateness of focus group research depends on whether research question can be addressed through the medium of group discussion. Krueger (1994) argues:

Focus groups are valid if they are used carefully for a problem that is suitable for focus group enquiry (p31)

Krueger outlines when the use of focus groups may be appropriate.

- I) when exploratory insights are required prior to a larger scale study.
- II) where there is a communication breakdown between one group and another - for example in professional relationships with clients or patients.
- III) where complex behaviours or motivations are to be uncovered.
- IV) where the researcher requires generation of ideas.

Oppenheim (1992) (p79) suggests that focus groups may be appropriate when the questions to be addressed are relatively straightforward and do not require long reflection, but will thrive from group interaction. Complex individual accounts may be best represented in in-depth interviews. Thus, the right question must be asked in a group setting, preferably one that promotes interpersonal interaction and discussion, (Esposito & Powell-Cope 1997).

The rationale for using focus group technique in this study is defined by Krueger (1994):

the purpose is to uncover factors relating to complex behavior or motivation. Focus groups can provide insight into complicated topics where opinions or attitudes are conditional or where the area of concern relates to multifaceted behavior or motivation (p31)

The aim of the use of focus groups in this study was to facilitate through discussion a background picture of attitudes and perceptions of the way in which consent is approached by nurses in clinical practice. This background picture would inform the more detailed account of practice achieved through the collection of data through critical incidents.

3.2.2 The development of and rationale behind focus group research

The history of focus group research is traced by Krueger (1994) (p7-10). The evolution of group research was developed by social scientists in the 1930s who were keen to explore alternative interview methods to the traditional interviewer-led approach using predominantly closed questions. The subsequent introduction of non-directional individual interviews using open-ended questions, still placed the interviewer in a prominent role. Attention was then turned to strategies whereby the interviewer could take a further reduced role. The group interview was introduced. The aim of the group interview was to generate discussion between group members, rather than dialogue directed at the group interviewer or moderator. It was hoped that this focus on group discussion rather than the individual questioning of group members, would help to achieve a reduced role of the interviewer. In order to achieve this, the focus group interview was developed.

However until recently, market researchers, who have used focus groups to shape marketing strategies, have largely used the method. In the more formal context of social science research, the use of focus groups was treated with caution due to a belief that interaction between participants was a form of respondent contamination, (Krueger 1995) (p525). However in the last few years, focus group technique has been readopted by social scientists and its role as a qualitative research methodology has been re-examined.

The rationale behind the use of focus groups as a data collection method is based on several principles:

Firstly, that an interview in which the interviewer takes a back seat may facilitate a different disclosure among participants from an interview, which is directed and controlled by an interviewer, (Macleod Clark et al. 1996). Kitzinger (1995) argues:

everyday forms of communication may tell us as much, if not more, about what people know or experience. (1995) (p299)

Krueger has taken this argument further to suggest that:

focus groups place people in natural, real life situations as opposed to the controlled experimental situations...Inhibitions are often relaxed in group situations, and the more natural environment prompts increased candour by respondents (1994) (p34)

While it can be claimed that a group discussion places people in a more natural situation than, for example those in an arm of a randomised controlled trial, the group is nonetheless convened. This group convention will affect disclosure.

Secondly, group interaction will guide the generation of data. The focus group interview facilitates group discussion. Comments from one participant generate others. This has been described by Stewart and Shamdasani (1990) as *synergism, snowballing, stimulation, spontaneity*.

Participants share ideas and test out their thoughts on other group members. This process facilitates further new insights and constructions. While discussion and the generation of new insights was also the aim of the critical incident interviews, discussion took place only between the interviewer and participant. Focus group discussion has the advantage that insights from many participants can be shared. McDaniel & Bach (1994) argue:

(the focus group) technique makes use of group interaction to stimulate subjects and provide insights and data that is not accessible without the stimulus of group discussion (p4)

The use of discussion to clarify meaning for the purposes of this research has already been identified (Section 3.1). That discussion can also be used to facilitate new insights has been observed by Barnes (1976) who observed the discussion of young children in a classroom. He observed how the comments of one child prompt a second child to continue the debate which he then throws back to the first child, who explores the ideas presented by his companion.

Focus group discussion can facilitate similar interaction. Krueger (1995) argues that:

focus groups allow participants to hear ideas and use these concepts in formulating their opinions (p530)

One group participant may raise an issue which had not been anticipated by another participant. However this prompts further thought and discourse. Furthermore, the statements of one participant can be validated and challenged by other group members. Kitzinger (1995) argues:

The idea behind the focus group method is that the group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview. When group dynamics work well the participants work alongside the researcher, taking the research in new and often unexpected directions, (p299).

The justification for the use of focus groups thereby relies on the argument that discussion will generate, test, clarify and articulate ideas to a greater extent than would occur in a one to one setting.

In view of this focus on group dynamics for the generation of data, it is often argued that focus groups are especially useful for exploring sensitive issues, where one to one interviewing may be intimidating.

Van der Vlist (1997) examined a programme in which the moral integrity of Dutch public servants was challenged through group processes. It was perceived that the topic was too sensitive to be approached on a one to one basis; or at least, the topic could be more effectively managed through a group process.

In a similar way, focus groups have been successfully carried out in health care with groups in which sensitive situations encountered by individuals, rather than potentially blameworthy behaviour, has been examined. For example, parents of handicapped children, people from ethnic minorities and partners of people living with HIV-AIDS have been the focus of focus group studies, (Bolla et al. 1996) and (Kitzinger 1994). A common theme to arise from these studies was that the discussion of shared experience was enhanced and facilitated by a permissive, empathetic and non-judgemental group.

3.2.3 The group effect in focus group data generation.

It has been suggested that in focus group research, group interaction in the form of discussion guides the generation of data. In this study, group interaction was sought in order to explore how consent prior to nursing care procedures is obtained.

The realities constructed in a group setting will differ from those constructed in a one to one interview setting because of the effect of being in a group. Firstly, although the technique enables the researcher to access the perceptions of many participants, it is important to recognise that 6 focus groups of 6 participants does not generate the equivalent data as 36

individual interviews. In view of this, it is recommended that the group itself, and not the individuals is the unit of analysis, (Morgan 1995) (p522).

Secondly, the group effect on the data generated must be considered. Albrecht et al (1993) examine the communication processes involved in group interaction. They observe that a consensus of opinion often emerges from a focus group discussion; a consensus that may not arise from individual interviews. They argue that this emergence of a consensus of opinion can be a result of the group interaction. That is, the constructions generated in a group will be intrinsically different from those created by the individual. However, they argue further that this consensus does not affect the usefulness of the data generated by the focus group. Individuals live and work in group settings and are never free from the influence of others. Social interaction affects both the formation and articulation of opinion (p55). Similarly, Macleod Clark et al (1996) argues that people do not live in a vacuum; their perceptions and opinions are socially constructed, (p149).

Albrecht et al (1993) suggests that three types of communication pattern can be evident in focus group discussion. These are compliance, identification (group think) and internalisation. They argue that internalised opinions are less susceptible to the effects of group participation and therefore may represent deeply held views. Thus, despite the usefulness and relevance of group generated data, Albrecht et al suggest that the key issue in focus group research is to elicit these internalised views.

Thirdly, the question of which participants contribute in focus group discussion must be considered. Stewart & Shamdasani (1990) and Macleod Clark et al (1996) argue that a strength of focus group technique is that participants speak only when they have a definite answer to a question; they are not required to answer every question as with an individual interview. However, this does not mean that some dominant participants will not attempt to answer every question, regardless of whether they have a definite answer. Clearly, the contribution of quieter members must be considered; silence will not necessarily be an indication that they agree with the arguments presented, (Asbury 1995) (p418).

Fourthly, the influence of others may effect the amount of disclosure that occurs within a group. Pressure to conform, for example, may inhibit free disclosure. Kitzinger (1994) found that ignorance about HIV disease seemed to earn respect from the focus group participants. This was a common theme that was identified across various groups and led to a perceived

reduced level of disclosure.

The ideal group facilitation should aim to ensure that group discussion is generated in a way that facilitates the expression of internalised thought and opinion and maximises contributions from all those who participate. The extent to which the focus groups undertaken in this study achieved these aims will be discussed later in this section.

3.2.4 Preparation for the use of focus groups

In preparation for undertaking focus group research and for the role as moderator, the author undertook a course in Focus Group Research in May 1997. The course emphasised the practical aspects of moderating focus groups.

As an introduction to the course, an example of a focus group was given to all course members. The example focus group was convened from course members who volunteered to take part and was moderated by a course leader. This focus group highlighted two important aspects of group facilitation. Firstly, the skill and ease with which the group was (apparently) moderated. A warm rapport was created, individual names of participants were used throughout and interest was expressed in every contribution. Secondly, that participation in a focus group was an interesting and enjoyable experience for those participating, giving each the opportunity to express his or her views. Clearly, this would not have been so without a skilled moderator.

Following observation of the moderation of a focus group, all course participants were given the opportunity to moderate a focus group discussion and received feedback on this process. The course was an enjoyable and valuable experience for the author, which supplemented the experience already obtained from a teacher preparation course for health care professionals. Although the emphasis of a focus group is essentially different from that of a group convened for educational purposes, the skills of creating a permissive environment for free discourse and disclosure, asking questions, probing and exploring responses can be seen as transferable skills.

3.2.5 The sample

The first task was to identify a sample of nurses who were willing and able to participate in a focus group according to the stated aims of the study. Krueger (1994), in common with most commentators of focus group research, suggests that a series of focus groups be carried out on a particular topic. This ensures that a wide range of people are involved in the discussion process and that the findings from one discussion can be compared against another.

In view of this, and for the practical reasons of planning working schedules, a target of six focus groups was set for this study. This was an arbitrary figure, although many studies comprise up to six or eight focus groups, it was necessary to prejudge the number of focus groups required in order that they could be prearranged in advance. Krueger (1994) (p18) identified that, fundamental to focus group research, as in any research, is the question: who do you want to hear from? Asbury (1995) argues that participants in focus group research should have the common experience that is the key to the research focus. While it might be argued that all nurses share this common experience, it was anticipated that their ability to articulate their opinions and challenge those of others may vary.

In view of this, a purposive sample of nurses who were willing and able to participate in discussion concerning how consent is gained prior to nursing care procedures was required. Purposive sampling and sample size is discussed in detail in Section 3.3.4. Thus, a process of intensity sampling was preferred, whereby participants were selected according to their perceived ability to articulate their opinions. It was therefore decided to select the sample from qualified nurses who were participating in post registration courses in higher education. It was considered that those undertaking higher education courses were likely to be familiar with the art of discussion, reflection and critical analysis. This 'elite bias' in the sampling, common in qualitative research is acknowledged. In addition, there were pragmatic reasons for selecting a sample from within higher education. Pressure on the time of staff working in the clinical area has led to difficulties in convening a focus group discussion with nurses on shift duty. Macleod Clark et al (1996) document a low attendance rate obtained when focus groups were held during time allocated to clinical duties. Indeed, Macleod Clark et al (1996) identified a need for over-recruitment of up to 50-100%. Reasons identified for poor attendance were lack of incentive payments and difficult attendance due to shift work and workload.

Furthermore, it was considered that participation in a focus group discussion was an educational activity in its own right. It was therefore justifiable to offer participation in a focus group as part of a university research module. If this could be negotiated, then nurses would be able to participate without feeling that time was being taken from clinical duties or indeed their educational courses.

3.2.6 Characteristics of the focus groups

The number of participants in each focus group ranged from 5-10 participants. All participants

were qualified nurses, studying for either a graduate or postgraduate qualification in nursing. Most researchers suggest that each focus group should consist of 6-12 participants. Krueger recommends that participants form a homogeneous group but where there is sufficient diversity of opinion to promote discussion, (1994) (p18). However, some researchers recommend relaxing the requirement for a homogenous group in order to gain greater diversity of opinion and challenging discussion within a group, (Dilorio et al. 1994) (p177) and Esposito & Powell-Cope (1997). Participants in this study came from a variety of clinical backgrounds which provided the diversity required to generate a rich discussion and comparison between clinical areas.

Krueger also recommends that, where possible, group participants are unfamiliar with each other and suggests that familiarity may inhibit disclosure (1994 p18) However, other researchers disagree. Kitzinger (1995), Macleod Clark et al (1996) and Dilorio et al (1994) found that familiarity in a group assisted group discussion and disclosure as opposed to hindering it. Participants in this study were familiar with one another, although they did not work together. Most researchers do agree that avoiding hierarchy within institutions is preferable in order to promote free discussion and emphasise the importance that individual group members are volunteers and not co-opted into participating in the group.

3.2.7 Access to research sites and invitation to participate

A series of six focus groups with qualified nurses studying for post registration degrees/diplomas in institutes of higher education were held between March and November 1997. The following process was undertaken in order to achieve this.

The heads of the academic nursing departments at two institutes of higher education were approached and permission was sought to negotiate holding focus groups within forthcoming scheduled research modules of the institution. (Appendix 2). Ethical approval to carry out the study was sought from the educational establishment's ethical committee. The tutor who held responsibility for the appropriate research module was then approached by the author, who was able to negotiate holding a focus group within the research module, as an example of qualitative data collection. The session would be 'opt in' so that no one felt coerced into participating in the study. Those who did participate would have to 'opt out' of the planned research session, which would run simultaneously. The arrangement was for the author to visit the students early on in the module, explain the research and the proposed focus group. The tutor would then ask if anyone was interested in participating and then contacted the author

with the names of those who had expressed an interest in the study. While this was a fairly labour intensive method of recruitment, it served the purpose of incorporating the research into the context of the research module. The tutors responsible for the modules were also enthusiastic to have a nurse researcher involved with the research course. The method of recruitment was also successful; each introductory visit to a module yielded enough participants to arrange a subsequent focus group. Six focus groups were undertaken in this way.

In three of the six groups, one of the participants who had initially 'opted in' to the focus group, decided to 'opt back' to the mainstream session. However, this did not affect the conduct of the focus group discussion.

Using this method of focus group recruitment, the challenges described by many focus group researchers of low response and turn up rate to focus group interview, were not encountered, (Morgan 1995).

However, the problem of selection bias, explored by Krueger (1994) (p80) was encountered. Those who participated were not selected at random. Participants who volunteered to opt out of the research module class to participate in the focus group may have had a hidden agenda or reasons for their participation.

In order to maximise learning from the experience of participating in a focus group, at the end of the session, those who had participated in the focus group rejoined the other students and were invited to describe the process to those who had not taken part. This was useful for research purposes as some informal feedback of participants' experience of focus group participation was obtained. Discussion of these experiences were not formally recorded.

3.2.8 Defining the questions to be asked in the focus group

The questions to be asked in the focus groups were initially discussed at Ph.D. supervision sessions. The importance of piloting the questions to be used in a focus group discussion is emphasised by Krueger (1994) (p68) and Morgan (1995) (p520). In this study, the questions were 'tested out' with students during the course of a teaching session on informed consent given by the author at a department of nursing at an institute of higher education, as part of an ethics module in February 1997. They were tested out to determine the extent to which they provoked discussion about the way in which informed consent prior to nursing care procedures is obtained. The following questions were refined for use in the focus group discussions:

1. How is consent gained prior to nursing care procedures?
2. For which procedures do we gain consent to nursing care procedures?
3. For which procedures should we obtain consent?
4. When is consent not obtained?
5. When may consent be unnecessary?
6. What are the problems/ difficulties in gaining consent prior to nursing care procedures?
7. What happens when a patient refuses nursing care?

3.2.9 Moderation of the focus groups

Focus groups were held in a room close to the parallel running plenary session. At the start of the session, participants were given the option to rejoin the plenary session and were assured of the confidentiality and anonymity of their participation. All groups were moderated by the author who introduced herself and repeated the aims of the study. The full participation of each participant was encouraged. Permission was sought to tape record the discussion, with the assurance that the tapes would be listened to and transcribed only by the author. Permission was granted by all six groups. The names of each participant was requested and these were recorded, together with the participant's corresponding seating position, as an aide memoir, on a sheet of paper.

The aim was to achieve an atmosphere in which participants felt free to articulate their own opinions about the topic of consent prior to nursing care procedures. Reiskin (1992) comments on the skills of the moderator in creating the initial environment for the focus group:

the moderator sets the mood of the group by creating a non-threatening, warm, accepting, enthusiastic and objective environment, which encourages all group members to share their views (p200)

Participants were given a written copy of the focus group questions and were asked to consider each question and record their response to that question. The purpose of this was to encourage each participant to consider each question prior to group discussion, to minimise the effect of compliance and group identification, and to maximise eliciting the internalised thought of participants, as identified by Albrecht (1993).

Facilitation of the group proceeded with attention to each question in turn. In this way,

participants could follow the structure of the discussion. The question was posed to the group, clarified or reworded if necessary until discussion was generated. The skill of striking the right balance between interference in the group discussion and generating additional interest has been widely discussed in the focus group literature, for example Sim (1998). When necessary, questions were responded to in a neutral but enthusiastic manner, in order to avoid leading the discussion. For example '*that's very interesting.*' Wherever possible, response was not given by the moderator, thus allowing other participants to add to the discussion.

The ideal qualities of a moderator are described by Krueger (1994) (p101). He suggests that the moderator should be comfortable and familiar with group processes and group dynamics. The moderator should exert subtle control over the group, guiding and prompting the discussion with appropriate questions. While the moderator is responsible for probing and asking specific questions which will direct discussion, it is essential that he or she does not attempt to summarise the discussion as it progresses, for risk of misinterpretation. This point is emphasised by many commentators on focus group research, for example, Carey (1994). Most importantly, Krueger (1994) emphasises that the moderator should be curious about the topic and respectful of the contribution offered by all group members.

Moderating skills were developed by the author as the focus group interviews were carried out. Some focus groups were easier to facilitate than others. In principle, where participants were keen to discuss the concept of consent prior to nursing care procedures, group discussions were easier to facilitate than those in which there was less enthusiasm.

However, where groups were enthusiastic, the question of how to deal with the unexpected or difficult situations arose. Esposito & Powell-Cope (1997) (p32), suggest that the moderator must be skilled in group dynamics and able to cope with unforeseen difficulties. Dilorio et al (1994) (p178) suggest screening for characteristics (for example, aggression) in potential participants which may hinder the group process. This process of screening was not possible in this study and hence greater emphasis was thrown onto the skills of facilitation. Furthermore, many researchers advocate the having two group moderators, (Krueger 1994) (p103), (Macleod Clark et al., 1996) (p147) and McDaniel & Bach (1994). A second moderator can pick up cues in tandem with the first moderator and assist in the management of difficult situations. However, due to the confines of this study, it was not possible to arrange for a second moderator to attend the focus group discussions. When participants were perceived to be dominating the discussion, techniques were employed to encourage the participation of others.

The tip of recording the name of each participant proved invaluable for this.

In principle, the focus groups were moderated successfully. A rich discussion was generated in all six focus groups. In the example given below, group interaction was used to establish initial ideas about consent prior to nursing care procedures. Each line of the verbatim script represents a different participant.

You go along and ask if you can do it.

Consent is mainly verbal

Very, very rarely ... I can't think of any incidents where you'd get written consent. (Focus group 4)

From this apparent description of a process whereby consent is obtained verbally, a participant added to these ideas saying that often, a verbal consent is not obtained. Whether information is given so that a patient can consent or withhold his consent is at the discretion of the nurse:

Discretion of the nurse really.

If you are talking about informed consent - depends on information given in the first place.

You tell them ... if you feel the need (Focus group 4)

These insights were obtained through the process of group discussion among participants. The moderator did not contribute to their construction. This example illustrates that the discussion generated in a focus group will be significantly different from that generated in one to one interview.

The focus groups were successful in obtaining some background exploratory data concerning the way in which nurses approach consent prior to care procedures. Although many participants had not considered consent in nursing prior to their participation in the study, this did not inhibit the discussion. Comments and observations made by one participant served to generate ideas and insights from others. General approaches to practice were compared and challenged, and ideas as to how practice could be approached were suggested.

It often became apparent in the course of a focus group that participants held misperceptions about consent that led, or indeed had the potential to lead, to significant infringements of the principles of consent. It was clearly important that these misperceptions were corrected. In view of this, the action of the author was to let the interview run its course and then at the end to discuss the principles of consent with the participants. Thus, in return for participating in the

focus group, the participants received some impromptu teaching on the principles of consent. This was without exception well received.

3.2.10 Commencement of data analysis during the focus group interview

The discussion generated in the focus group interviews marked the commencement of data analysis. Krueger (1998) (p47) emphasises the evolutionary nature of the discussions; how participants change their perceptions as they are challenged by other group members. This free flowing exchange of ideas is an initial analysis of the ideas presented.

It is often commented that data analysis commences at initial interview. Kvale (1996) (p189) argues that the process of data analysis is commenced by the participant in the interview as he or she discovers new relationships and meanings in the events described.

Kvale is referring to one-to-one interviews in which the role of the interviewer is to challenge the participant in the development of new ideas in order to achieve clarification of meaning. The dialogue between interviewer and interviewee shapes the final constructions. In focus group research, this initial analysis is different. The role of the moderator in the focus group discussions is to facilitate the group discussion but not to engage or heavily influence it. Therefore, in the focus group discussions undertaken for this study, the participants, rather than the moderator challenged one another and meanings became clear as the discussion progressed. The moderator's role was to facilitate the discussion that would uncover these meanings, but not to participate in the identification of these meanings, or at least, to participate as little as possible. The group, not the facilitator was engaged in the formulations of constructions. Thus, the group discussion marked the commencement of data analysis.

3.2.11 Transcription of focus group interviews

All focus group discussions were tape recorded and transcribed by the author. Transcription was undertaken directly onto Word for Windows files to ease subsequent analysis. Each tape was listened to several times to ensure accuracy of transcription. Transcription was carried out immediately after the focus group to facilitate accuracy. The intonation, emphasis of the words used and laughter were noted in the transcription. Informal observations and field notes taken at the time of the group were also recorded.

The transcripts were read and re-read to ensure familiarity with the data. The aim of this process was for the author to achieve a good comprehension of the data, (Morse 1994b) (p26).

The context in which the discussion took place and the influence of the group effect were examined.

All six focus group interviews were transcribed and re-read in this manner immediately after the interview. Many qualitative research theorists (for example, Strauss & Corbin (1990) and Lincoln & Guba (1985), advise that data collection and analysis are carried out simultaneously. This is especially applicable in grounded theory, in which the on-going analysis informs the subsequent collection of data. In this study, data analysis was not used to guide the sampling strategy. A pre-set number of focus groups had been predetermined. In this study, data collection and initial analysis were carried out in close succession in order to facilitate accuracy in the transcription.

3.2.12 The process of constant comparison

Following the transcription and comprehension of the focus group transcriptions, the texts were prepared for further analysis. The aim of this stage of the analysis process was to compare one section of data with another following the principles established by Glaser and Strauss (1967) (p105). These principles have been applied by Lincoln and Guba (1985) to the area of naturalistic research and advocated in focus group research by Krueger (1998) (p17). Incidents in the data are coded into categories of analysis. As new incidents are coded they are either used to create new categories or to fit into an existing category.

Glaser and Strauss (1967) (p105) describe four stages in the constant comparison method.

1. comparing incidents applicable to each category
2. integrating categories
3. delimiting the theory
4. writing the theory

The way in which these stages were used in this study are described below.

3.2.13 Identification of the unit of analysis

The first task was to identify the unit of analysis for coding the data into categories of analysis. Lincoln and Guba (1985) (p344) suggest that a unit of analysis should have two characteristics. Firstly, it should provide some understanding or action. Secondly, a unit must be the smallest piece of information that can stand on its own. It should be interpretable in the absence of any additional information other than a broad understanding of the context in which the inquiry is

carried out.

Many focus group researchers emphasise that it is the discussion, not the individual comments made within the discussion that forms the unit of analysis in focus group research, (Krueger 1998) (p20), (Carey 1994) (p233) and (Macleod Clark et al. 1996) (p150). Krueger emphasises that the discussion is evolutionary, building on previous insights and observations made by other group members. Individual comments can be taken out of context if they are not interpreted within the meaning of the discussion in which they were articulated. In view of this, the unit of analysis of the focus groups in this study was taken to be a section of discussion, which related to a discrete aspect of consent prior to nursing care. In this way, the group discussion could be analysed in manageable units.

69 identifiable units of analysis relating to the practice of obtaining consent prior to nursing care procedures from the focus groups were identified. Data which did not relate to nursing practice or which meet the criteria for a unit of analysis was discarded. A unit of analysis is presented in the section below.

3.2.14 Coding each unit of analysis

Each unit of analysis was coded at two levels. A unit was initially given an outline code, describing its major happening. It was then given a descriptive code, detailing the meaning of the unit. Coding was inductive. The code was derived from a broad description of the meaning of the discussion.

An example of a unit of analysis and its coding is given below. The unit of analysis is the discussion of whether the patient's acceptance of a procedure is an indication of his implied consent or merely his compliance. The outline code given to the unit was *how is consent obtained?* The more detailed, descriptive code was *compliance or implied consent?* Each line represents the contribution to the discussion made by a different participant. Additional commentary on the incident is also made in bold. It is important to note that these comments are made about the whole unit of analysis and do not refer to an individual's statement.

Outline code: how is consent obtained?

Descriptive code: Compliance or consent?

*It (consent) can be implied, can't it body language take off their cardigan before you get to them
.... it's implied that they gave consent.*

H.A: Do you feel that is a consent?

We certainly take it as a consent

H.A: Is it? Is compliance consent? Did you mean compliance or did you mean something slightly different? (example of leading question to generate discussion)

No no, I probably mean compliance. (distinction between compliance and consent)

H.A: Or is there a difference between implying consent and a patient being compliant?

I suppose if you are actively doing something like taking your cardigan off, I would say in the broad sense you are being helpful aren't you ..so that's consenting rather than being compliant. (is there logic here?)

I would say compliant ... as opposed so letting somebody take your clothes off(challenge of above statement)

.... but I think you would seek a verbal consent anyway ... is it alright if ...?

H.A: You wouldn't rely on the implied ? (further questioning to generate discussion)

You don't tend to say, can I do your blood pressure sometimes you do, but other times you'll just say, I've come to do your blood pressure and they take their cardigan off, which is a

..... it implies somebody's consent. If the opportunity is there to say no, then they don't take the opportunity.

H.A: And is the opportunity there to say no, do you think?

Maybe the way we phrase our questions doesn't give them a chance

Can I take your blood pressure. Yes. They feel they can't say no.

H.A: Do you think they can say no?

Yes. They often say I'm doing something at the moment, can you come back later, or I'm just going for a fag or something and we'll say OK we'll do it later. They don't always say yes OK.

I've actually heard patients say in a joking fashion when you've gone up them and said I'm going to do your blood pressure, is that OK? And they've said well you're going to do it anyway aren't you. I've heard that said on occasions. The patients are taking it as well that's what I'm here for sort of thing (challenge to above statement).

Focus group 5

3.2.15 Peer involvement in the coding of data.

The purpose of peer involvement was to elicit alternative observations and insights in the data and to challenge insights made by the author. Two colleagues were involved in the coding process. Both colleagues had training in moral philosophy and qualitative research and were invited to comment on one of the focus group interview transcriptions and to challenge the coding that had been carried out.

Lincoln and Guba (1985) describe this process of peer involvement as a process intended to “*explore aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind*”(p308). Given that value free interpretation of the data is regarded as impossible, this additional peer interrogation of the data is recommended as a credibility check, to keep the inquirer ‘true’ to the data and to challenge formative conclusions formed. The influence of subjectivity and ‘author bias’ in the data analysis are discussed in Section 3.3.9.

The insights and challenges of peer review of focus group transcripts need to be considered in view of the fact that the colleague had not been present at the focus group discussion and therefore had not experienced the discussion first hand. However this process of peer involvement and interrogation of the data proved to be a valuable source of discussion.

3.2.16 The creation of categories

Initial coding was undertaken of the first two focus groups. The outline codes from these units of analysis were then used to create broad categories. Units of analysis which had been assigned similar outline codes were grouped together. These groupings formed provisional categories which were assigned provisional descriptions. Lincoln and Guba (1985) define the process of categorising as a process of devising rules –

that describe the category properties and that can ultimately be used to to justify the inclusion of each unit that remains assigned to the category as well as provide a basis for later tests of replicability and to render the category set internally consistent (1985) (p347)

A provisional name was created for each category. Lincoln and Guba suggest that the category should be named in a way that clearly determines the rules for inclusion into the category. An

emerging outline of categories was created from the coding of the first two focus group discussions. Subsequent coding of the remaining focus groups were then either used to create new categories or to fit into existing categories. At this point the process of constant comparison was fully employed. As each unit of analysis was coded and allocated a category, the description of the category and the content of the existing units in the category were re-examined to determine the appropriate allocation of the new unit of analysis.

3.2.17 Reconsidering the name of a category and the allocation of units into a category

On the basis of this constant comparison, the new unit of analysis or an existing unit could be re-deployed if either were felt not to fit the emerging category, or the description of the category could be amended. As this process continued, additional coding did not lead to the creation of additional categories, but consolidated and refined the categories already in existence. As Lincoln and Guba (1985) describe:

It is this dynamic working back and forth that gives the analyst confidence that he or she is converging on some stable or meaningful category set. The test is two edged, exposing both incident and category to searching criticism. (p342)

The position of each unit of analysis and the name of each category was reconsidered and relocated where appropriate. Three outline categories were created. The categories were created from a process of induction. However the influence of the author on this inductive process should be acknowledged. The author approached the focus group analysis with an understanding of informed consent as presented in Chapter 1. On analysing the data, the categories created fell into the three aspects of consent as outlined in the principles given in Chapter 1.

How is consent prior to nursing care procedures obtained? (Consent is mainly assumed. Explanations are given as to why)	(43 units of analysis)
The patient refuses or is reluctant to accept nursing care.	(15 units of analysis)
The patient is not able to consent to nursing care.	(11 units of analysis)

Because of the broad descriptions of the categories, all of the units of analysis for the focus group data, which referred to consent obtained prior to nursing care procedures were applicable

to one of the categories.

3.2.18 Development of the properties of each category.

Following the development of the three outline categories, the sub-categories or properties of these categories required consideration. The categories were broad and contained a wide range of descriptive codes. These codes needed sorting within the category. Each category was analysed for the diversity of codes within it and to develop its theoretical properties or sub-categories. Glaser and Struass (1967) define this process:

the analyst starts thinking in terms of the full range of types or continua of the category, its dimensions, the conditions under which it is pronounced or minimised, its major consequences its relation to other categories and its properties.(p106)

Units of analysis with similar codes were compared, continuing the process of comparison analysis. For example, comparison of the units within each category shed light on the meaning of a particular unit where the meaning was ambiguous. An example of this was the ambiguity of the meaning of the unit of analysis presented above. The unit was initially understood, and sub-categorised as 'consent is implied'. Further consideration and comparison led to its relocation to a sub-category named 'patients are compliant'. Its final allocation was to a sub-category entitled 'are patients compliant or do they imply their consent?'

The units of analysis in the sub-categories were arranged in the form of a story or logical argument that took account of all the happenings in the category. A storyline, created from the happenings in the category, began to emerge. This process is discussed in Section 3.3.24.

3.2.19 Analysis of deviant cases

The analysis of deviant cases is discussed in Section 3.3.17. In the focus group study, units of analysis were compared and contrasted in order to establish the meaning, as described in Section 3.2.18.

3.2.20 Use of the questions discussed in the focus group in the data analysis

Krueger (1998) advises that the questions discussed are the raw material of subsequent analysis (p23) He advises that key questions that are of primary concern to the research question drive the group discussion. In this study, the questions were used as prompts to generate discussion on the key question of how consent prior to nursing care procedures is obtained. Some of the

questions were fairly similar. Although the same question schedule was used in each group discussion, questions had different 'discussion generating' effects in the different groups. In one group, for example, a topic was discussed in response to the first question, whereas in another group, the topic was discussed in response to a different question. In view of this, data generated by different questions are not analysed separately in this data analysis. Given that all questions were aimed to address the topic of how consent prior to nursing care procedures is obtained, individual questions aimed at eliciting this data are not central to the analysis. However, the effect of the question in shaping the course of the discussion was addressed.

3.2.21 Member checking

The process of member checking of one-to-one interviews is described in Section 3.3.20. The reasons why member checking was not undertaken in the critical incident study are outlined. It is argued that analysed data is not recognisable to the original participant who cannot recognise his or her contribution within the data analysis. Returning analysed data to those who participated in the study can therefore be unhelpful. In a focus group study, the same principles apply. However, given that the group discussion is the unit of analysis, the whole discussion can be summarised and returned to the participant for content and meaning verification. Even so, the same worry exists. Participants may feel that their contribution was inadequately portrayed in the summary and hence challenge the summary.

However, in this study, the opportunity arose to contact those who participated in one of the focus groups via the module leader, who had offered any further assistance. In view of this, a summary of focus group five was made and sent to those who participated via the module leader. The participants were asked to examine the summary and comment as to the extent to which they felt it represented the previously held discussion. Unfortunately, the module leader did not remember to return these summaries to the participants. Instead the request was returned to the author some months later.

3.2.22 Delimiting the theory

Following the process of analysis outlined above, fewer modifications were made to the categories and their properties. This process is referred to by Glaser and Struass (1967) and Lincoln and Guba (1985) as delimiting.

as delimiting occurs the original list of categories will be reducable in size because of improved articulation and integration ; options need no longer be held open. At the

same time, categories become saturated, that is, so well defined that there is no point in adding further exemplars to them (p344)

Some qualitative research theorists regard this process of saturation with scepticism, regarding the concept as a 'vanishing horizon', which is never reached as the researcher remains immersed in the data, (Miles & Huberman 1994) (p62). However, towards the end of the processing of coding, the codes assigned to the focus group discussion units became repetitive. At this point, Glaser and Strauss (1967) suggest using theoretical saturation as a means of dealing with new data. If the coding of an incident does not identify new dimensions of a category, but reinforces those already established, it can be discarded to avoid adding bulk to the data analysis.

The understanding of how nurses perceive consent prior to nursing care was achieved through the integration of categories. As a result of this process of comparison analysis, categories of meaning emerged. The content of each category had been scrutinised for appropriateness of content. This categorisation of units of analysis of the focus group discussion provided an overview of how consent prior to nursing care procedures is approached by nurses had been obtained. One category informed another or provided an explanation for phenomena identified in another category. For example, the unit of analysis presented above is evidence of a discussion as to whether a patient's behaviour indicates an implied consent or merely compliance. This category was entitled compliance or consent. Another category contained units of analysis referring to the passive role that patients are observed to play in hospital, indicating that patient behaviour may be attributable to compliance rather than a genuine consent. In this way the categories created by the coding of the focus group data were collated to form an understanding of the way in which consent is perceived by nurses.

3.2.23 Theorising

The final categorisation of the focus group study is not presented independently in this thesis. The results are integrated with the results of the critical incident study. This is to ensure that the exploratory work of the focus group informs the in-depth study of how consent is addressed through the collection of critical incidents. A discussion of how the theorising of both the critical incident and focus data was undertaken is given in Section 3.3.24.

3.3 Critical Incident Technique to explore how consent is obtained prior to nursing care procedures.

3.3.1 The use of critical incidents in the present study

The data collected through the use of focus group provided some detailed exploratory data concerning the way in which consent is obtained prior to nursing care procedures. However descriptions of care were general not patient-specific. The data offered insights into nurse attitudes and perceptions of consent, not the reality of everyday nursing care situations. In view of this, critical incidents concerning the way in which consent is obtained prior to nursing care procedures were collected as a means of achieving specific information about the way consent is obtained. Participants were asked to identify incidents in practice concerning consent prior to nursing care procedures. These incidents were discussed in-depth at interview.

The critical incident technique was selected as a means of examining how nurses obtain consent prior to nursing care procedures because it facilitated the observation of practice in addition to the opportunity to explore and reconstruct the meaning of practice with the participant who described the incident.

Many researchers in ethical inquiry have argued that the discussion of real life critical incidents will produce an account of ethical practice that reflects the reality of practice more closely than the discussion of hypothetical incidents, (Holm et al. 1996) and (Grundstein-Amado 1993). Grundstein-Amado (1993) identified a difference between theoretical and practical ethical reasoning. They argued that asking participants 'what did you do' in a real life situation was more conducive to achieving an objective account than asking participants 'what would you do' in a contrived situation. Use of the Critical Incident Technique therefore avoids the criticism often aimed at the qualitative interview, (Silverman 1998); that there is a wide gap between what people say and what they do.

3.3.2 The development of the Critical Incident Technique

The Critical Incident Technique was developed and described by Flanagan (1954) as a result of studies in the Aviation Psychology Programme of the United States Army Airforces in World War II. The Aviation Psychology Programme was established in 1941 in order to develop procedures for the selection and classification of aircrews (Flanagan 1954) (p326)

One of the aims of a series of studies was to define and describe the components of a successful bombing mission. Pilots and their instructors were asked to record critical incidents which were

perceived as effective or ineffective in the bombing mission. The use of critical incidents as a means of observing and analysing behavior was preferred to vague generalised statements about behavior. The critical incidents were analysed and the required criteria for a successful bombing task were determined. Flanagan (1954) described:

The critical incident technique, rather than collecting opinions, hunches, and estimates, obtains a record of specific behaviors from those in the best position to make the necessary observations and evaluations. (p355)

Flanagan argues that the Critical Incident Technique can be used as a means of observation of practice. The more detailed the account, the more likely the account is to be accurate. Flanagan argues:

if full and precise details are given, it can usually be assumed that this information is accurate (p340).

From these early studies, Flanagan (1954) defined the terms critical and incident:

Incident: any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act (p327)

For an 'incident' become 'critical' it: must occur in a situation where the purpose or the intent of the act seems fairly clear to the observer and where its consequences are sufficiently definite to leave little doubt concerning its effects (p327)

Interestingly, the focus of the early use of critical incident technique was the acquisition of objective accounts of practice. Flanagan (1954) emphasised the importance that observers of critical incidents are clear as to the purpose of the activity being examined:

the accuracy and therefore the objectivity of the judgments depend on the precision with which the characteristic has been defined and the competence of the observer in interpreting this definition (p335)

Despite this, Flanagan claims that "only simple types of judgments are required by the observer"(Flanagan 1954) (p335) However, it might be argued that the correct identification of

a critical incident according to Flanagan's fairly rigid criteria require more than just a simple judgment. That is, the observer of a critical incident must be able to judge the significance of the incident and its relevance to the topic under investigation. Indeed, Flanagan specifies the judgments which must be made by an observer:

- i. Is the actual behavior reported?
- ii. Was it observed by the reporter?
- iii. Were all relevant factors in the situation given?
- iv. Has the reporter made a definite judgment as to the criticalness of the behavior?
- v. Has the reporter made it clear just why he or she believes the behavior was critical?

Thus, incidents, which contribute to an understanding of the topic of the study, must be easily identifiable to the observers. Except in rare circumstances, the researcher or initiator of the study will not be the main observer of critical incidents.

It could be argued that in the early studies of bombing missions, it was possible to identify critical incidents, which met Flanagan's criteria. The components of a successful bombing mission are largely clear cut; success or failure is immediately apparent. In addition, those observing and identifying critical incidents were often pilot instructors who were well qualified to judge what was critical and what was not. However some of Flanagan's early studies involved the identification of critical incidents by the pilot-in-training himself. In this case, success of the technique is reliant on the ability of a less experienced observer to identify critical incidents. It might be argued again that the clear cut success / failure of bombing missions will be immediately apparent to a junior pilot and that he is also thereby suitably qualified to observe critical incidents and thereby produce an objective account of the successes and failure of a bombing mission.

3.3.3 The development of the use of the Critical Incident Technique within nursing research

Flanagan acknowledged that the procedure, which enabled him to define the components of a successful bombing mission, may not be appropriate for another research setting. He argued that the approach should be flexible:

It should be emphasised that the critical incident technique does not consist of a single set of rules governing such data collection. Rather it should be thought of as

a flexible set of principles which must be modified and adapted to meet the specific situation at hand (p335)

In observational contexts other than a bombing mission it may be less easy to identify critical incidents which provide a valid insight into the situation or event under study. The success or failures of nursing care may be less easily captured and recorded as critical incidents than the components of a bombing mission. Whether or not use of the critical incident technique produces a comprehensive observation of events under study depends on the ability of the observers to identify incidents, which will contribute to an accurate description of the event under examination. These incidents may not be easily identifiable in nursing care. Incidents will therefore be subjectively selected and may not provide a comprehensive account of practice.

Furthermore, nurse researchers have questioned the extent to which nursing care procedures lend themselves to identification through discrete critical incidents. Norman et al (1992) found that many 'critical incidents' as identified by consumers were not clearly demarcated incidents that stood alone for independent analysis. They did not fulfil Flanagan's criteria as critical incidents. They found that patients tended to refer to overall experience and they did not always distinguish between what happened on a certain occasion. In addition, they felt that repeated happenings may be more significant than one off incidents. Norman et al (1992) conclude that in complex human-human interaction (as opposed to the more predictable human-machine interaction), this may be an inevitable and natural result and argue:

Human beings are complex creatures with varied histories and memories who create and recreate meaning within the social situation they experience. The implication of this is that incidents cannot be abstracted from the chronological temporal flow of human experience. The meanings of critical observed happenings which are located within incidents are not created anew but are the product of previously created meanings which are carried forwards from previous incidents. As such, human beings will inevitably describe one incident in the light of related incidents and the meaning of observable events is of crucial importance. (p599)

For these reasons, Norman et al (1992) suggest that the critical incident itself may not be the most appropriate unit of analysis. They suggest that 'critical happenings' that are revealed by the incident, may form the basis of analysis. Critical happenings occur within an incident, but

do not constitute a 'critical incident' in themselves. They suggest the term 'revelatory incident' is preferable to 'critical incident'.

The use of critical incidents in nursing research may vary from Flanagan's early development and use of the technique. The critical incidents, which contribute to an observation of practice will necessarily have been selected subjectively by those who participate in research.

Furthermore, critical incidents may not be identifiable as discrete events. Critical happenings may be a preferred observational unit. However, critical incident technique has been widely utilised in nursing research as a valuable means of observing practice without intrusion into the clinical setting. Furthermore, this observation can be analysed, discussed and reconstructed with the research participant who recalled the incident.

3.3.4 The sample

In order to achieve in-depth accounts of nursing practice concerning the way in which consent is obtained prior to nursing care procedures, detailed critical incidents from an articulate and diverse group of nurses was required. In view of this, sampling for this study was purposeful.

Purposeful sampling is defined by Patton (1990) as the selection of:

information rich cases for study in depth. Information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research (p169)

One strategy for purposeful sampling described by Patton is a close reflection of the sampling strategy undertaken for this study. Patton (1990) describes the strategy of intensity sampling (p171) whereby information rich cases are selected that manifest the phenomenon of interest. In this study, a purposeful sample of nurses who were willing and able to recall and discuss critical incidents relating to consent prior to nursing care procedures was required. The aim of collecting the critical incidents was to achieve a rich observational picture of the way in which consent prior to nursing care procedures is obtained. This picture would be achieved through observation of practice through critical incidents and importantly, through participants' reconstructions of these incidents. Thus a prerequisite for participation in the study was the ability to articulate and reflect on incidents recalled. A process of intensity sampling enabled the selection of potential participants who were considered to be articulate providers of information rich critical incidents.

Coyne (1997) argues that the distinction between purposeful and theoretical sampling be made explicit in nursing research, arguing that the two are often used interchangeably. Theoretical sampling was not a feature of this research because the sample requirements were predefined. It was considered that an observational and reconstructed account of the way in which consent is obtained prior to nursing care procedures could be obtained from critical incidents and reflections presented by a purposeful sample of nurses as described above.

The size of the sample required for qualitative studies has been discussed in the research literature. Morse (1994a) suggests that 100 observational incidents are required for an observational study while 30-50 interviews are required in an interview study. Meanwhile Sandelowski (1995) argues that while sample size is important, principles of sampling strategies might be a better guide of sample size than arbitrary figures. She suggests:

A good principle to follow is: An adequate sample size ..is one that permits – by virtue of not being too large – the deep, case-orientated analysis that is a hallmark of qualitative inquiry, and that results in – by not being too small – a new and richly textured understanding of experience (p183)

In view of this, the number of critical incident interviews was not predefined at the beginning of data collection, but constantly reviewed over the course of the data collection period. A final total of 30 interviews were carried out. At this point, a rich data set had been achieved to which significantly new themes were not being added. Although at this stage of the research, a state of 'saturation' (discussed later in this chapter) had not been systematically identified, it had been estimated from initial impressions of the data that had been collected. The author's aim was to complete the analysis of 30 interviews and then to review whether saturation had been achieved.

3.3.5 Access to research sites and invitation to participate

Two teaching hospitals in central England were identified as potential research sites. These sites were selected due to their geographical location and their status as teaching hospitals attached to university departments of nursing. An 'intensity rich' rather than a representative purposeful sample was sought. In view of this, it was considered that teaching hospitals involved in the education and training of undergraduate nurses would be likely to employ nurses with the ability to articulate their experiences of how consent is obtained and to give

their interpretations of these processes.

General medical units were chosen as the location for the study due to the number of medical wards in the unit and the (untested) perception that nurses on medical wards would be less likely to associate the concept of consent with surgical procedures than those working on surgical wards.

Ethics Committee approval was sought and obtained from the respective committees in each Trust to collect critical incidents through interviews with nurses on medical units. (Appendix 3) In addition, approval and support to undertake the study was obtained from the Director of Nursing at each of the Trusts and the managers of individual units. Many of those contacted expressed their interest in the study. (Appendix 4)

The nurse manager of a selection of medical wards was subsequently contacted in order to seek permission to carry out some interviews with staff, if possible, during clinical time. When this agreement had been obtained, managers were asked to identify staff who they perceived might be interested in participating in the study and who they felt might provide 'rich' data. The manager then gave each potential study participant a letter outlining the study. (Appendix 5) The manager was contacted again one week later by the author who subsequently received a list of potential participants who had agreed to an interview. These nurses who had positively responded to involvement in the study were contacted by telephone to arrange an interview. This was an extremely 'labour intensive' approach to inviting participants to interview. However it was an approach that minimised the potential for nurses to feel obliged or pressured into participation in the study as there was no contact with the author until they had given a preliminary agreement to participate. In addition, the approach undertaken ensured that each level of nursing management was familiar with the study and did not hold an objection to nurses under their management taking part in an interview during in clinical time wherever possible.

Details about the interview had been outlined in the letter given to the potential participant. These details were repeated in the telephone call. Nurses were asked to identify and prepare to discuss three or four incidents relating to consent to nursing care procedures, which had recently arisen in clinical practice. For the purposes of this study, a nursing care procedure was defined as any nursing intervention in which the nurse is the final person to carry out the care procedure. For example a nurse administering intravenous fluids, would constitute a nursing

care procedure even though it has been previously prescribed by a doctor.

3.3.6 Characteristics of nurses who participated in critical incident interviews

A total of 30 interviews were conducted. 17 were conducted at one teaching hospital and 13 at the other. All nurses were qualified to a minimum of Registered General Nurse and had a minimum of six months post registration experience. Clinical grading of those who participated ranged from D to G grade.

3.3.7 The process of interviewing

Flanagan (1954) (p331) suggests that interviewing is the preferred method of collecting critical incidents in order to obtain a detailed account of practice. In addition, for the purposes of this thesis, use of interviews is essential for the discussion, reflection and reconstruction of that incident.

With a few exceptions, most participants had prepared well for the interview. They attended the interview with a rich array of critical incidents which they were keen to discuss. Many participants commented how much they had enjoyed the interview process and that they had learned from the experience.

The interview process required two specific skills on the part of the interviewer. Firstly, it was necessary to ensure that a full account of the critical incident had been identified and recounted by the participant. Participants had a tendency to recount only sections of the incident. It was often necessary to prompt and re-prompt the participant to recount the incident from the beginning in order to facilitate maximum detail of the incident. Subsequently, it was necessary to facilitate a discussion of this incident that reflected the meaning and significance of the incident for the participant. The interviewer's skills in these areas developed as the process of interviewing continued. However, on transcribing the interviews, the inevitable gaps in the meaning of the dialogue were identified which could have been filled by appropriate questioning.

In constructivist research, the inquirer and inquiree shape the course of the interview. However, it remained important that the eventual interpretations were those based on the construction of the participant, who had been involved in the incident, not the interviewer. The interviewer was therefore concerned to minimise the extent to which the participant's responses were influenced by leading questions or to accept the interviewer's interpretations that were not

intended. For example, in the following excerpt, it is likely that the participant was led to accept a particular conclusion. The construction of the dialogue does not convince the reader that the eventual meaning reflects the participant's interpretation of the incident. The participant had described an incident in which a patient had been reluctant to undergo a procedure. It was the interviewer's intention to discover whether the participant felt that she used her discretion in the amount of persuasion employed to persuade the patient to accept the procedure. She accepted this but did not clarify why she felt this.

H A: Might you get a heavy handed nurse (I'm playing devils advocate here) who felt that 30 minutes of interrogation was OK?

or that a heavy handed nurse might have gone straight in and not bothered to ask the patient?

H.A: or can you imagine someone else talking to her for half an hour? Were you using your discretion as to how much she could take of persuasion?

yes I don't think I'd have carried on more than 10 minutes, I mean I wasn't saying "come on you must have it" I was talking about the reasons...I think any longer, if she had been adamant, it would have been unfair to have grilled her for any longer than that...I'd have pulled away and tried again later, having got advice, or got another colleague to go over... (Interview 10)

The intention here was not to lead the participant to interpretations which he or she did not truly accept. The following example illustrates how interaction between the interviewer and the participant resulted in clarification of the participant's meaning but did not impose an unintended meaning. The participant was prompted to reflect on the significance of issues that arose and the interpretation of the incident was refined and clarified as the discussion continued.

you develop a relationship and in a relationship you have communication... and that's how we exchange information and find out what peoples' needs are.....having already conducted part of the assessment, you then add to that, what their previous experiences were and what they need to know...

H A: So would you say that a model for consent would be that it is implicit within nursing, and not a separate thing that you do?

yes I think that is a really good way of putting it. (Interview 18)

In principle, the collection of critical incidents through in-depth interviews was a successful, if labour intensive way of obtaining an observation of the practice of obtaining consent prior to nursing care procedures. Participants were generally very well prepared and gave detailed accounts of practice which they were keen to explore.

As with the focus group interviews, it often became apparent in the course of an interview that participants held misperceptions about consent that led, or indeed had the potential to lead, to significant infringements of the principles of consent. In view of this, following the interview, a general discussion about the principles of consent was held with the participant.

3.3.8 Critical incidents or critical happenings?

Sensitive to the defining attributes of a critical incident and the difficulties encountered by Norman et al (1992) in achieving such a collection of incidents, the author was interested to observe that the nurses who participated in the interviews did not experience difficulties in the

identification of discrete critical incidents. A total of 88 discrete critical incidents relating to nursing care procedures were identified. An additional 15 incidents which related to non-nursing incidents were also identified. However, as per Norman et al's experience, many care episodes which did not amount to a discrete incident were also identified. Many critical happenings were also identified. These critical happenings were often identified during initial discussion at interview or between the recount of specific critical incidents. In view of Norman et al's argument that critical happenings represent significant happenings in nursing care procedures, these happenings have been included in the data for analysis.

It was felt that the collection of these critical incidents had provided an in-depth account of the way in which nurses approach consent prior to nursing care procedures. An observation of practice, supplemented by the participant's interpretation of that practice had been achieved.

3.3.9 Commencement of data analysis during the interview.

The use of in-depth interviews as the method of collecting critical incidents served two purposes in this study. Firstly, it was a way in which to obtain the participants' account of the incident and clarification of any point that remained unclear. Secondly, it provided the opportunity to discuss the incident with the participant and to facilitate their articulated reconstruction of the incident. This discussion facilitated the immediate commencement of data analysis.

Kvale (1996) (p189) argues that the process of data analysis is commenced by the participant in the interview as he or she discovers new relationships and meanings in the events described. This analysis is then continued by the interviewer who adds further interpretation to the relationships and meanings in the continuing dialogue. Kvale argues that:

This dialogue ideally continues until there is only one possible interpretation left, or it is established that the subject has multiple and possibly contradictory understandings of a theme (p189)

The value of the use of discussion to facilitate the reconstruction of the incident was evident in the collection of interviews in this study. Kvale (1996) (p3) describes two philosophical approaches to interviewing. In the first approach, the interviewer is compared to a miner who understands knowledge as buried metal to be discovered. It is unearthed without the use of leading questions or other contamination which might influence its meaning. In the second

approach, the interviewer is compared to a traveller who has conversations with those he encounters. In the course of these conversations, both the traveller and the native find new meanings in what is described. Kvale (1996) comments:

through their own story telling, may come to reflect on previously natural-seeming matters of course in their culture (p4)

Using a constructivist approach, the collection of critical interviews in this study reflect a combination of these approaches. While the straightforward account of the incident as described by the participant was essential to the study, the aims of the study also required that the incident was interpreted and reconstructed by the participant and interviewer. This reconstruction comprised an initial form of data analysis.

Strauss and Corbin (1990) discuss the effect of the researcher on the process of data analysis. They describe the concept of theoretical sensitivity as a necessary prerequisite for any researcher. Theoretical sensitivity is defined as:

the attribute of having insight, the ability to give meaning to the data, the capacity to understand, and capability to separate the pertinent from what isn't. All this is done in conceptual rather than concrete terms. (p42)

They describe how sensitivity may be derived from various sources including professional experience and knowledge and is essential as it helps the researcher to:

understand events and actions seen and heard and to do so more quickly than if you did not bring this background into the research (p42)

They also warn how these experiences may block the researcher from seeing things that are routine or obvious and cause attention to be focused on what the researcher is looking for.

It is inevitable that the constructions of the application of informed consent theory held by the author will have affected data analysis. The author approached the study with an understanding of informed consent gained as a result of a MA in Medical Law and Ethics. This understanding served to convince the author that consent should play a significant role in nurse patient relationships as argued in Chapter 1. Furthermore, evidence that the application of informed

consent theory prior to nursing care procedures was not widely considered as argued in Chapter 2 may have influenced the approach of the author to the data. Furthermore, various experiences of teaching qualified nurses has given the author the impression that many nurses do not have a working understanding of the concept of consent. It was with these preconceptions that the interviews were conducted and analysis approached.

3.3.10 Transcription of interviews

All the in-depth interviews were transcribed by the author onto a computer.

Transcription was undertaken directly onto Word for Windows files to ease subsequent analysis. Each tape was listened to several times to ensure accuracy of transcription. Once transcribed, an incident was identifiable only by number. Transcription was carried out immediately after the interview to facilitate accuracy. The intonation, emphasis of the words used and laughter were noted in the transcription. The transcripts were read and re-read to ensure familiarity with the data. The aim of this process was for the author to achieve a good comprehension of the data, (Morse 1994b) (p26).

In the critical incident study, as in the focus group study, data analysis did not guide the subsequent collection of data. A pre-set number of 30 interviews, yielding about 100 critical incidents were carried out. In view of this, data collection and initial analysis were carried out in close succession in order to facilitate accuracy in the transcription.

3.3.11 The process of constant comparison

The process of constant comparison analysis is described in Section 3.2.12. Further analysis of the critical incidents was carried out according to the guidelines laid down by Lincoln and Guba (1985); who refer extensively to the method of constant comparative analysis initially devised by Glaser and Strauss (1967) (p105). While originally a method for deriving grounded theory, Lincoln and Guba argue that the method of comparison analysis can be used as a method for processing data.

Lincoln and Guba (1985) (p340) challenge Glaser and Strauss's assumption that categories simply 'emerge' from the data. They provide guidelines as to how the derivation of categories may be achieved. These guidelines were followed in the continued analysis of the critical incident data.

3.3.12 Identification of the unit of analysis.

The first task was to identify the unit of analysis. As mentioned in the focus group study, Lincoln and Guba (1985) (p344) suggest that a unit of analysis should have two characteristics. Firstly, it should provide some understanding or action. Secondly, a unit must be the smallest piece of information that can stand on its own. It should be interpretable in the absence of any additional information other than a broad understanding of the context in which the inquiry is carried out. In the analysis of critical incidents, information units are identified at two levels. At the first level, the entire critical incident, as per Flanagan's definition (1954) (p327) was identified as a unit of analysis. On the second level, happenings contained within the incident, as per Norman et al's (1992) definition are identified as the unit of analysis.

103 critical incidents were identified. A total of 88 critical incidents concerning consent prior to nursing care procedures were identified from the interview transcripts. A further 15 critical incidents were identified that related to consent prior to medical or other procedures. These 15 incidents were not analysed further. In view of the fact that participants had come to the interview with pre-identified incidents, incidents were, in the main, easily identifiable.

3.3.13 Coding the critical incidents

Incidents were coded by examining the incident and assigning to it a description of its major happening. The code was derived from a broad description of the event described. Coding was inductive, not predetermined.

In the critical incident analysis, each incident was coded at three levels. An incident was initially given an outline code, describing the major happening in the incident. For example, for the incident cited below, the outline code was *a patient unable to consent*. An incident was then given a more descriptive code, giving greater detail. For the incident cited below, the more descriptive code was *a patient unable to consent / wife insists on care given and this is followed*. Thirdly, the critical happenings within the incident were coded, as outlined below. The first twenty incidents were coded in this way. Although there were many interesting aspects of each incident (critical happenings), it was fairly easy to identify the major happening in the critical incident.

An example of a critical incident as a unit of analysis and the coding is presented below.

Outline code: patient unable to consent

Descriptive code: patient unable to consent / wife insists on care given and this is followed.

when I was training a gentleman had had a stroke and his wife was a nursing sister and she very definitely didn't want a catheter inserted (wife objecting to nursing care procedure). he was so... profound stroke it had affected his speech, he couldn't make his wishes known. his wife was adamant he didn't want a catheter inserted... (wife claims she is speaking for her husband but no evidence of this) we respected that decision, we tried with conveens, he got very very exscrolled because of the urine.. (consequences of not carrying our care procedure) no matter how bad he got, his wife was insisting "no I don't want a catheter put in" although it was a poor situation, from a consent point of view, it was really well observed... (participant belief that consent from a wife should be observed) we wouldn't argue with this woman anyway, she knew her husband and she felt he would not want that. we just abided by her decision. (uncertain whether the staff respected the wife's decision because they felt it reflected the husband's decision or whether they would have respected her decision anyway) in some respects it was wrong because of the suffering and discomfort he went through, but it was still his decision. he nodded his assent throughout. I have mixed feelings whether it was a good or a bad thing... the staff were very angered that they were putting themselves through this. what have they got against a catheter.. it would make his life so much easier... no-one really forced her hand one way... one or two people felt this "is ridiculous. why don't we just put a catheter in... it's for his comfort. it was decided that we can't really do that. it shouldn't be a case of us deciding for somebody, it's still their body at the end of the day. (is the participant aware of 'best interests' principle when the patient cannot consent?) she knows what her husband feelings are. In the end, he was on the ward for months and I left, to my knowledge he never had a catheter.. if he got very excoriated he had pad and pants which I felt was very degrading for him.. he was a grown man, having to be in a nappy... but when he wasn't sore, he got a conveen on and it worked reasonably well

H how would you manage it if it happened again?

I think I would manage it in the same way.. there's nothing... if someone was very adamant they didn't want it in, I'd explain the pros and cons, but the decision they've made at the end of the day "if you don't want a catheter were not going to put a catheter in" (participant makes no distinction between the wife and the patient's decision)

H even when it's a relative?

even when its a relative. if its a close relative, I think... what's a close relative?... I would follow the relative's wishes on the whole.

H do you think there is ever a case for not following a relative's wishes?

in something like that I don't know that there is. if they were dead set against it, I don't think I would actually go against that... I would just say "this is your decision.." (participant prepared to accept relative's decision)

H do you think it should be the relative's decision?

I think it should be the patients decision, but where the pt had a profound stroke, if a wife or a son, its fair enough for them to make the decision. they know the relative, we don't Interview 9

3.3.14 Peer involvement in the data analysis

Two colleagues were involved in the coding process; each coded five critical incidents. While Norman et al (1992) (p597) recommend that all of the critical incident transcripts are scrutinised by an independent researcher, resources prevented this in the present study. The process of peer involvement and interrogation of the data proved to be a valuable source of discussion. The purpose of peer involvement is discussed in Section 3.2.15.

3.3.15 The creation of categories.

Having assigned an outline code a descriptive code and coding of the happenings within the first twenty critical incidents, the initial process of creating categories was commenced. Lincoln and Guba (1985) (p349) suggest that some categories may be subsumable under others. This was the rationale for the different levels of coding. Outline categories were created from the outline code given to each incident. Within each outline category were many properties or sub-categories, derived from the more detailed coding.

Incidents which had the same or similar outline codes were grouped together. These groups formed provisional categories. The process of categorising as described by Lincoln and Guba (1985) is described in 3.2.16. A provisional name was created for the category. Lincoln and Guba suggest that the category should be named in a way that clearly determines the rules for inclusion into the category.

Having provisionally named the category and established these basic rules for inclusion / exclusion of incidents in the category, each of the incidents in the category were reviewed to ensure that their inclusion was justified according to the established rule. Any incident which on reflection did not fit the category was removed. The remaining 68 incidents were then coded in the same way, assigning each to one of the named categories. In order to do so, the basic rule for constant comparative analysis defined by Glaser and Strauss (1967) was adhered to:

while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category (p106)

3.3.16 Reconsidering the name of each category and the allocation of incidents into each category.

When all the critical incidents had been coded and allocated to categories, all the incidents in each category were re-examined to check each had been appropriately assigned according to

the rules of the category. In doing so, it was possible to integrate the basic rule as defined by Glaser and Strauss into the various stages of analysis. Incidents which seemed inappropriately assigned were then reallocated. The name of the category was reconsidered to ensure that it was an accurate reflection of the content of the critical incidents included. As described in Section 3.2.17, the data was compared back and forth so that a meaningful data set was achieved. In this study, three clearly demarcated outline categories derived from the amalgamation of outline codes were apparent. The categories were created from a process of induction. However, as mentioned in the discussion of focus group analysis, Section 3.2.17, the influence of the author on this inductive process should be acknowledged. The author approached the focus group analysis with an understanding of informed consent as presented in Chapter 1. On analysing the data, the categories created fell into the three aspects of consent as outlined in the principles given in Chapter 1.

These were:

1. Critical incidents in which consent is assumed: 4 + many critical happenings
2. Critical incidents in which the patient is reluctant or refuses nursing care: 33
3. Critical incidents in which the patient is not able to consent: 43 (+8 incidents in which the patient is sedated, not analysed)

As in the focus group study, the broad descriptions of the categories ensured that all of the units of analysis that referred to consent obtained prior to nursing care procedures were applicable to one of the categories.

3.3.17 Analysis of deviant cases

Examination of incidents or happenings within the incident that did not confer with the main body of analysis was undertaken. This occurred throughout the process of constant comparison analysis as outlined above. Patton (1990) (p463) suggests that failure to find an explanation for deviant cases strengthens their position as deviant; and that perfect patterns will be viewed with scepticism.

3.3.18 Development of the properties of each category.

Glaser and Strauss (1967 p107) suggest there will be two types of properties; explanatory properties that are constructed by the analyst and descriptive properties that are abstracted from the language of the data used by study participants. In this stage of analysis, where the critical incident is the unit of analysis, the aim of analysis is to achieve an understanding of incidents

described by nurses. For this reason, the categories are all descriptive. The properties within the category are firstly descriptive but become explanatory.

Coding and forming categories as outlined facilitated the constant comparison of incidents in a category and between different categories. The categories were broad and contained a wide range of incidents. Following the formulation of the three outline categories, it was necessary to examine the content of the categories. Each category was analysed for the diversity of incidents within it and to develop its theoretical properties.

In this study, each incident (unit of analysis) had been assigned an outline code and a descriptive code. The outline codes had been used to develop the three outline categories. The next step was to examine the descriptive codes in order to develop the properties of the category. The descriptive codes within each outline category were examined. Incidents holding similar codes were compared, continuing the process of comparison analysis. For example, one incident concerned a patient who was unable to consent to care, but who seemingly resisted intervention. The participant's articulate and vivid description placed much weight on how the nurses interpreted this resistance and how this determined their approach to care delivery, although ultimately care was given. The initial impression given was that nurses are guided by these nonverbal cues when a patient cannot consent; an approach which could result in patients not receiving the care they required. However, analysis of other incidents involving patients who were unable to consent identified that while many nurses toyed with the idea of responding to the apparent resistance of a patient who could not consent and were generally unsure how to proceed, none actually let this resistance determine care given.

The different descriptive codes within each outline category were also compared. This grouping of incidents in each outline category facilitated an understanding of the data obtained. The critical incidents were arranged in the form of a story or logical argument that took account of all the incidents in the category. A storyline, created from the incidents in the category began to emerge. This process is discussed in Section 3.3.24.

Following the development of the properties of the outline categories, the third level of coding was developed. Third level coding referred to the coding of the details of the incident. These details can be described as critical happenings within an incident.

3.3.19 Coding each critical incident for critical happenings.

In order to develop the properties of each category, each critical incident in each category was re-examined. Incidents had been coded for critical happenings. Each incident in each category was examined on a line by line basis and the critical happenings of each critical incident was identified.

There were two main aims for the coding of critical happenings. Firstly, to complete a further comparative analysis of the incidents in each category. Incidents, which, on further analysis seemed to be mis-categorised were reallocated. The second aim was to examine in detail the critical happenings within each incident. This enabled the further identification of the properties of each category. The development of the properties of each category was inductive, properties were identified from the critical happening contained in the incident. Further development of the properties was led by the data contained in the critical happenings.

3.3.20 Member checking

The complex process of member checking as described by Lincoln and Guba (1985) (p314), whereby the data, or analysis of the data are returned to those who participated in the study, was not undertaken. The reasons for this were both practical and theoretical. On a practical level, resources were not available to accommodate member checks on a representative sample of participants. Furthermore, theoretically, the arguments of Sandelowski (1986) and Koch and Webb (1996) were accepted. These researchers argue that it is unhelpful to return the data to participants in any format. Koch and Webb (1996) emphasise that a tape recording of the interview provides an account of the interview conversation. Subsequent analysis of the data will contain one participant's account within the account of others, which may not be recognisable to the participant. The participant's account may be hidden within the multiple realities constructed from the data analysis. Sandelowski (1986) argues:

researchers strive to represent multiple realities in a way that remains faithful to each members reality. I have found in my own work that members are sometimes more interested in concrete descriptions of their own experiences than in abstract synthesis that incorporates them with other members experience (p5)

Thus participants and researchers have different views concerning the representation of a fair account. Furthermore, participants may have changed their perception of the data since the interview took place. After the interview, the participant may have assigned a new meaning to the events described. Sandelowski argues:

they represent members' efforts to order, find meaning in and even live with the events in their lives at a particular moment in their lives. Stories previously told may elicit feelings members no longer have (p5)

For these and other reasons, the tape recording of the interviews provided a verifiable account of the data collected.

3.3.21 Delimiting the theory

Following the process of analysis outlined above, the identification of three main categories and their properties became more secure, as fewer modifications were made to the categories and their properties. Towards the end of the processing of coding, the codes assigned to the critical incidents and happenings became repetitive. At this point, any new data which did not add to the meaning of the categories was discarded. This process is referred to by Glaser and Struass (1967) and Lincoln and Guba (1985) as delimiting and is described in Section 3.2.22. Using the critical incident as the unit of analysis had the advantage that the data had not been fragmented. All the critical incidents had been categorised in their complete form. On completion of this stage of analysis, a map of the critical incidents in the study had been achieved.

3.3.22 Electronic assistance for data analysis.

Word for Windows was used to assist data analysis in both the focus group and critical incident studies. The author attended a training course for the use of NUD*IST 4, although due to financial constraints, this programme was not used for the qualitative data analysis described in this section. Use of Word for Windows, in a similar manner to that used in this study has been described by Burnard (1998). Each critical incident and focus group had been transcribed onto a file. As coding was undertaken, a file was then created for each identified category. The unit of analysis – critical incidents or sections of discussion – were then cut and pasted into the category file. As the category was refined, incidents and discussion sections were relocated appropriately. When the properties of each category were developed, in the critical incident study, incidents were reorganised in the file to facilitate the logical ordering of incidents. The inductive description of how consent is obtained could then be identified. Copies of files before recategorisation were retained as an audit trail of the analysis process. In addition, a file containing all critical incidents and focus groups was created so that incidents could be easily re-identified and retrieved using the EDIT-FIND control.

3.3.23 Trustworthiness of the focus group and critical incident study

Lincoln and Guba (1985) define four criteria by which the value or trustworthiness of constructed inquiry can be assessed. These are credibility, transferability, dependability and confirmability, (p301-331). The way in which each criteria applies to the present study will be examined in turn. The first criteria for establishing trustworthiness is to establish that the findings are credible. This can be determined in part by examination of the inquiry process. For this reason, the inquiry process is given in detail in this thesis. The inquiry was undertaken by the author who had knowledge of both the clinical setting and the concept of informed consent. Furthermore, the author possessed the communication skills required for successful interviewing and analytic skills for successful analysis. The inquiry was undertaken in good faith, with rigorous attendance to the methodology described. Initial findings of data analysis were scrutinised and some were independently analysed. Analysis was methodical and systematic, using the procedures described earlier in this chapter. However the process remains necessarily subjective. A more astute inquirer, or one approaching the inquiry from a different angle might have achieved a different perspective. Lincoln and Guba (1985) (p329) suggest that the reader of a constructivist inquiry cannot be compelled but only persuaded to accept the findings presented. It is hoped that the discussion of the method of inquiry and the present discussion of credibility will persuade the reader that the findings are trustworthy and can be reapplied in a relevant context.

Two deviations from Lincoln and Guba's (1985) (p301-316) criteria for credibility are discussed below. The justifications for these deviations are summarised. Lincoln and Guba emphasise the importance of inquirer engagement in the research setting, arguing that "it is not possible to understand any phenomenon without reference to the context in which it is embedded" (p302). In this study, critical incidents and focus group discussions were obtained from qualified nurses in various clinical locations. It was therefore not possible for the author to achieve prolonged engagement in each clinical setting. As a compensation for this, it was ensured that all participants in the study were working in the same clinical setting (general medical units) as that which had been the clinical background of the author.

Member checking was not undertaken. The reasons for this are discussed earlier. Given the current debate as to the value of member checking, and the justifications made for not including such a process in the present study, it is not felt that its omission is a serious threat to the credibility of the findings of this study.

It is suggested that the constructions of those who participated in this study represent a credible account of the way in which consent is obtained prior to nursing care procedures. The accounts are necessarily subjective, but as argued earlier in this chapter, might be the closest means of achieving a realistic account of a complex nursing practice.

The extent to which the findings of this study are transferable is an assessment which can be made only by those interested in applying the findings elsewhere. Lincoln and Guba (1985) (p316) describe the process of transferability and suggest that it is the responsibility of the inquirer to provide a data base of evidence that makes it possible for the reader to assess whether the findings are applicable in another context. For this reason, an extensive amount of data is included in this thesis in order to demonstrate the context in which the data is set and the meaning ascribed to the data in the analysis.

Lincoln and Guba (1985) (p316) argue that a study cannot be valid unless it is dependable. Thus if a study is credible, it ought by the same criteria, to be dependable. However, they suggest that the process of auditing, whereby the inquiry process and product are examined, can confirm dependability. No such audit was undertaken on the process or product of this inquiry. However, detailed records of the inquiry process have been retained for the purposes of such auditing should it be required.

The recording of an audit trail is also required by Lincoln and Guba (1985) (p318) for the purpose of determining the confirmability of an inquiry. The following audit requirements have been collated for this purpose. Raw data of each individual and focus group interview has been kept electronically and on paper. All the data is anonymous. Initial and subsequent data analysis has been retained to demonstrate the process and development of analysis. These early analysis reports document the ways in which the meaning of the findings developed as the analysis progressed. They demonstrate how early findings from the data were sometimes refined, rejected or confirmed. In addition to these reports of early analysis, the inquirer's field and observation notes and hunches are recorded.

Lincoln and Guba's (1985) criteria for establishing trustworthiness in a constructed inquiry have been attended to as far as possible within the constrictions of carrying out this thesis. Trustworthiness might have been enhanced by the undertaking of a greater number of interviews, by an increased amount of independent analysis, greater insight on the part of the inquirer and a greater amount of time which could be devoted to the study. However within the

limitations of the inquiry, an understanding of how consent is obtained prior to nursing care procedures has been developed. The different facets of this understanding do not contradict each other but link together, adding weight to the individual arguments developed and validity to the emerging picture.

3.3.24 Theorising

In view of the complex nature of obtaining consent, nursing practice was examined through the constructions of those involved with obtaining consent in clinical nursing practice. These were obtained through the exploratory data obtained from the focus groups and the care-specific data obtained from the critical incidents. The categories of the critical incident data and focus group discussion are examined together in the final theorising of the study. This was important to ensure that the exploratory work of the focus group informed the in-depth study of how consent is addressed through the collection of critical incidents. In most of the sections of each chapter, data from the critical incidents and focus groups are integrated. In principle, the exploratory data from the focus groups is presented prior to the specific observational data provided in the critical incidents. However, given that some exploratory data was obtained during the critical incident interviews, the distinction between exploratory and observational data cannot be strictly maintained. In each chapter, the themes and sub-themes derived from the analysis of the data will be discussed in depth.

The process of theorising was undertaken on completion of the process of constant comparison analysis. Analysis of the focus group and critical incident data were considered together. Morse (1994b) describes this process:

Theory is developed from comprehending and synthesising data...Theorising is the constant development and manipulation of malleable theoretical schemes until the 'best' theoretical scheme is developed. (p32)

The different aspects of the data were re-examined to explore the ways in which one aspect of data informed another. Following this process, the data was ordered in a way that provided a rich description of the way in which consent is obtained prior to nursing care procedures. As Morse (1994b) describes:

Theorising may be considered as the sorting phase of the analysis. Briefly it is the systematic selection and fitting of alternative models to the data.(p33)

The theory developed from the data analysis is presented in chapters four, five and six. The chapters are data driven. They represent the systematic sorting of the categories derived through the data analysis. Many of the critical incidents and focus group discussion sections are given in full throughout the presentation of finding. In this way, an audit trail following progression of the data analysis to the final arguments and conclusions of the study can be clearly identified.

The findings are grouped according to the principles identified in Chapter One. These three principles reflect the three categories induced from the data analysis and form the foundation of the three results chapters.

Chapter Four: How is consent obtained prior to nursing care procedures? The nurse should recognise those procedures that require the patient's consent and ensure that in these instances the consent is valid; that the patient is aware and substantially informed about the procedure and free from coercive interference.

Chapter Five: The patient who refuses or is reluctant to accept nursing care. The nurse should respect the patient's substantially autonomous refusal.

Chapter Six: The patient who is unable to consent to a nursing care procedure. The nurse should not seek consent from those patients who are unable to give it. The patient should be cared for in his or her best interests.

3.3.25 Summary of the composition of categories derived inductively from the analysis of critical incidents and focus group discussion.

Description of categories, derived by induction.	Number of unit of analysis from 6 focus group discussions	Number of critical incidents from 30 interviews
How is consent obtained prior to nursing care procedures	43	4 (+ many critical happenings)
The patient who refuses a nursing care procedure	15	33
The patient who is unable to consent	11	43 (+ 8 incidents in which sedation is administered to a patient, recorded in Appendix 6
Data referring to consent prior to non-nursing procedures	Not recorded	15

4 CHAPTER 4: HOW IS CONSENT OBTAINED PRIOR TO NURSING CARE PROCEDURES?

4.1 Data included in this chapter

Inductive analysis of 103 critical incidents identified 4 critical incidents and many critical happenings, which illustrate how consent prior to nursing care procedures is obtained. These data are reinforced by exploratory data contained in 11 units of analysis from the focus group discussion. Some of these data are presented and discussed in this chapter.

The critical incident and focus group data provide evidence of how consent prior to nursing care procedures is obtained in the absence of complicating factors (patient refusal or inability to consent) which are described in later chapters.

Before the data is discussed, it may be useful to document some features of the in-depth interviews in which the critical incidents and happenings were collected, which led to the identification of critical incidents and happenings in this chapter. Throughout the in-depth interviews, there was much discussion about consent prior to nursing care in general. These impromptu recollections were usually less specific than those relating to specific critical incidents. They contained descriptions about how consent is gained prior to nursing care procedures. While these impromptu recollections often prompted participants to remember and identify specific critical incidents that they had not initially intended to discuss, they do not constitute critical incidents in themselves (as per Flanagan's definition, 1954). However, they provide further evidence as to how consent prior to nursing care procedures is obtained.

Events which do not constitute a critical incident, have been described as critical happenings by Norman et al (1992). Norman et al (1992) suggest that one clinical event is often described in relation to another. The boundaries of the event may not be well defined. For this reason, it can often be difficult to obtain 'entire' critical incidents from participants in a study. In view of this, Norman et al suggest that 'critical happenings', or 'revelatory happenings' which describe an aspect of care but which do not constitute a critical incident, can be collected instead. In this study, participants gave many critical happenings, which describe the ways in which consent is obtained prior to nursing care procedures.

How should the significance of these critical or revelatory happenings be assessed in the analysis? Should it be argued that complete critical incidents bear more weight than less complete critical or revelatory happenings? Flanagan (1954) suggests that the reliability of a

critical incident lies in its detail, (p340). That is, the more detail that is contained within an incident, the more likely it is to be an accurate observation of practice. Therefore, discrete detailed critical incidents in which the whole incident is described may be a more reliable and accurate description of nursing care than that provided by incomplete incidents or critical happenings. There is evidence that some nurses do not do what they say they do. (Norman et al 1994) Reports of practice that are recounted as critical incidents may be less open to this inaccuracy than those which contain only a generalised account of nursing practice.

The suggestion that a critical happening provides less reliable evidence than a complete incident, is not to suggest that it is less significant and its evidence should not be used. On the contrary, in this study, the observation that participants were unable to cite discrete critical incidents describing how consent is obtained prior to nursing care procedures adds weight to the evidence presented in the critical happenings and the argument presented in this chapter:- that consent is largely not obtained. It is suggested that, for this reason, participants were not able to describe the process. This is contrasted with the development of the following two chapters in which participants described whole clearly demarcated critical incidents describing specific problems concerning consent prior to nursing care procedures.

It has already been remarked that consent is a complex process which may not be easily identifiable. However through the process of data analysis, a strong picture of the way in which consent is obtained prior to nursing care procedures emerges.

4.2 Nursing care procedures carried out following minimal or no explanation.

There is evidence that many nursing care procedures are carried out following minimal or no explanation. In the focus group discussions, participants discussed how much nursing care is carried out following minimal or no explanation. One main theme to emerge from all group discussions was that participants felt that consent prior to nursing care procedures is very often 'assumed'; that is, that consent is not obtained. The following discussion is representative of group discussions. A line spacing divides the contribution of a different participant.

H.A. How is consent obtained prior to nursing care procedures?

It isn't

It's implied

I think we assume a huge amount. We assume consent is implied (Focus group 1)

Another conversation ran as follows:

I still think we don't get consent for most things.

We assume consent to personal care. I'm trying to think if I've ever heard a nurse ask consent for a blanket bath.

You do the (observations) ...you get them out of bed, you just do it (Focus group 4)

Later in the discussion, the participants returned to this topic:

Everything is based on assumption. That is traditional.

Maybe once when you were admitted to hospital you expected the medical profession to have the power, now I don't think that's the case. Just thinking about it, there are so many times you don't get consent - just doing observations.

*Prescribing medication and giving it . . . we don't say 'do you give your consent?'
There's so many things we just do.*

It's frightening really. (Focus group 4)

A participant in another focus group described:

You say, "I've come" You never say "is it all right / to come and take some blood?"
(Focus group 2)

A series of critical happenings provided by a participant provides an example of how consent is

assumed; that is not obtained. In these happenings, patients who are unconscious following a head injury are initially unable to consent to having a naso-gastric tube, (ng tube). In the absence of consent, the tube is inserted because it is clinically indicated. However, when the patients regain consciousness, despite their resumed capacity to consent, patients are still not given the opportunity to consent. If, for whatever reason the naso gastric tube needs to be reinserted, this is automatically carried out without asking the patient.

They (patients who have had a head injury) pull their naso-gastric tubes out. We just put them back in.... there's no discussion...they don't know what is going on so I suppose... we're justified in putting it in because they don't know what is going on. When they get better and they start knowing what it is for and they still pull it out, they still don't get asked if they want it back in (laugh)...I never asked anyone and I've never heard any one ask anyone...it's kind of "this is to feed you, you'll get better if you're fed." Therefore you obviously want it...(Interview 2)

The participant cited further examples in which nursing care procedures are carried out with minimal explanation or choice of alternative options. She described:

They should be asked a lot more than they are.... for a lot of the mundane things you don't even think to ask.. it's like patients have to have a wash. I've never asked a patient. I ask them do you want a wash now or later but I never ask do you want a wash or do you not want a wash..(laugh) mundane things, giving injections. I can't remember the last time I asked someone. If they are in pain, I ask them do they want tablets or an injection...but it's like subcutaneous heparin. I don't tend to ask I just go up and say "I've got this for you" and assume they will accept it. so far they always have. I never ask ...(Interview 2)

Another participant described how many nursing care procedures are undertaken in a routine manner, with minimal explanation; with an expectation that patients will comply. She described:

Taking a blood pressure... I suppose we don't ask... well... I do say 'do you mind if I take your blood pressure?' because I've got to go up to them...a lot of patients are older and expect to comply... the younger ones you tend automatically to give them more information, I don't know why. They are going to demand it so you might as well

give it straight away. (Interview 7)

Another participant commented:

Taking the patient's blood sugar, we don't get consent. we go along and say "I'm just going to take your blood sugar..". we don't tell them what it's going to be like, we don't explain... OK some people know, but we just say " I need to take a bit of blood from your finger...it's down to the uniform, they trust. (Interview 27)

Another participant gave a clear example how, in her view, patients were cajoled into accepting care:

I see patients being cajoled out of bed...where does consent and where does bullying come in? You explain to someone the dangers of lying in bed, they may get pressure sores, bad for the chest, I don't like to see a nurse say to a patient "you've got to get out of bed" they are adult. I can see the way some of the nurses do it is really not the most appropriate way...you do have to be quite forceful, but I would not get someone out of bed without their consent.

H.A. Is it more the way it is done than the intention behind it?

Yes, I'm sure of that really, it's the way it's done. most patients say "OK nurse" (Interview 19)

There is evidence that some nurses give no or minimal explanation to patients prior to carrying out some nursing care procedures. None of the participants suggested that only those who were familiar with care procedures received minimal explanations. Furthermore, minimal explanation can result in patients being unaware about the care they receive.

4.3 Patients are often uninformed about their care

Clearly, if patients are not given information about care procedures - and they do not receive information from another source - they will not be informed about their care. Indeed, one participant in an in-depth interview admitted that many patients do not know about the care they are receiving. She described:

I don't think we do get consent. I went up to a patient and said "I've got your antibiotics, where's your needle?" I didn't say "would you like your antibiotics...?" (laugh) I just gave them. I told him what I was doing, but the family said "do you know what she's giving to you?" joking.. he said no...

H.A. How do you feel about that?

I suppose we ought to be asking, but they are here for the treatment. I suppose if they didn't want it they could refuse... (this was expressed doubtfully) I don't know...they don't get any option to refuse..... (Interview 7)

Another participant described the same situation:

Some long term patients, on heart tablets say, you assume they know what they are for...but then you ask them a question about it and you realise they haven't got the remotest idea what they are taking...they have a blind trust. very odd. Patients who are on heparin... you go up to them and say, no one ever asks, very rarely, they may say "what's that injection for" I ask them which particular site they'd like to have the injection. A lot of patients, you go up to them and they have been in hospital for about a week. You say to them, "where would you like it and do you know what its for" and they say "I don't know what it's for, I had it stabbed in my arm yesterday and it bled a lot" So I don't think people gain consent for every injection. (Interview 2)

The participant continued:

Like senna liquid, it's disgusting. You think I'm glad it's not me. I'm glad I don't need it. But then you think do they need it? There are alternatives. You assume they will go along with it and unless they object you don't give them an alternative....it's only when you step back from it all. When you're at work up to your eyes..it's only when some one does ask questions that you realise that you didn't ask him in the first place. You realise you go through the average day and haven't asked the patient anything. You assume you are acting in their best interests. You know best. They know you know best. You don't ask. It's how it is. Some disgusting medicines.. It's so surprising that patients go along with it. I wouldn't do it. (Interview 2)

It is of note that this participant expected that the patient would fit into the plan of care activities. She continued:

You do it (nursing care) regardless of your patient. Your patient will fit in. ... You adjust your nursing to the average patient who doesn't ask. It's only when you sit down and think, would I want this done?

(Interview 2)

There is evidence that for much of nursing practice, consent prior to care procedures is assumed, that it is not obtained. Patients are not given information about the proposed care and as a result are often uninformed about the care they receive. It has been argued in Chapter 1 that consent is required prior to those care procedures that threaten patient autonomy. There is no indication in the data cited above as to whether the care procedures prior to which consent was assumed was not perceived to threaten the autonomy of the patient; that is, whether on this analysis, consent was unnecessary. However, further indication of this is presented in the data below.

4.4 Is consent prior to nursing care procedures implied?

While acknowledging that patients are often not informed about their care, many participants expressed the view that the patient's consent prior to nursing care procedures was somehow implied. One participant described:

There is nothing that nurses do, that we document that we have got consent, even though certain things, like putting down naso-gastric tubes, are an invasive procedure, we never get patients to sign. they don't consent in that manner. (Interview 20)

The participant suggests that although the patient has not signed a form, he or she may have given their consent in a different manner. The way in which consent is expressed may be open to variation. Consent may be expressed formally, in a written statement, expressed verbally or it may be implied, implicit in the actions of the patient. The term implied consent has been described by Fleming (1998). He describes:

Consent may be given expressly, as when a patient authorises a surgeon to perform an operation, but it may just as well be implied. Actions often speak louder than words. Holding up one's bare arm to a doctor at a vaccination point is as clear an assent as if

it were expressed in words...Failure to resist or protest indicates consent if a reasonable person who is aware of the consequences and capable of protest or resistance would voice his objection. (p87)

Fleming argues that if a patient is aware of the consequences and does not register any protest at imminent intervention, then his consent has been given by implication. Implied consent is accepted in law. The concept dates back to the Canadian case *O'Brien v Cunard SS Co. (1891)*. In this case the plaintiff alleged she had not given her consent to vaccination on board a ship bound from Queenstown to Boston. The court held that the plaintiff should have been aware of the need for vaccination due to the information displayed around the ship in various languages about quarantine regulations, information about vaccination and when vaccinations would be available. The court held that the surgeon who administered the vaccination had the right therefore to presume that the passengers understood the need for vaccination and that when they joined the queue at the vaccination point they implied their consent. The court held that if the plaintiff's actions were such as to indicate consent on her part (offering her arm for vaccination), the surgeon had been justified in proceeding with the vaccination, whatever the unexpressed feelings of the patient may have been. Thus the principle was established that the patient's consent does not have to be written or spoken; it can be implied.

Implied consent is accepted in law. Fleming argues that if a patient is informed and does not resist the intervention, then his or her consent can be said to be implied. The standard of information required may be different from a legal perspective than from an ethical perspective. However what is important is that implied consent requires that the patient is informed. Implied consent is a consent, it merely lacks verbal or written affirmation.

Many nurses described how consent prior to nursing care procedures was obtained neither in writing nor indeed verbally, but implicitly or non-verbally. Many nurses felt that consent prior to nursing care procedures is implied. One participant described:

A lot of nurses get consent non-verbally. (Interview 20)

That is neither in writing or orally, but by implication. How is this implied, non-verbal consent obtained? A minority held view, expressed by two participants was that when a patient is in hospital, he has given an implied consent to all inherent procedures. One participant described:

I feel patients adopt a patient role, they come into hospital and expect nurses to do things to them..everything for them so in one sense, because the consent has already been given...

H.A. By coming into hospital?

By coming to hospital

(Interview 24)

The vast majority of participants did not agree with this point of view. They did not feel that admission to hospital amounted to an implied consent to any possible care procedure. One participant described:

If you don't encourage people to ask questions, they won't. So then you say- well they didn't ask...but they weren't given a chance... people think a patient in hospital has consented to everything that is needed to get them out of hospital.

H.A. Do you think that is a valid assumption?

Not always... where people are compos mentis, it's a bit hard to assume, you sort of assume whatever you do to them, if it's for their good, they will accept however unpleasant. You assume they want to get out of here as quickly as possible, therefore they consent. (Incident 2)

Most participants felt that being in hospital did not signify their consent to whatever was proposed. Indeed such a proposition is not in line with principles of informed consent which require that a patient can withdraw his or her consent at any time, thus ruling out any such blanket approach to consent in health care.

One participant describes how, in her view, consent is implied by patients prior to nursing care procedures.

90% of the day you are getting consent, but you aren't registering it, but it's just common decency to say to patients "do you mind" but it doesn't register as consent. "I'm about to take your blood pressure...would you like a wash?" ... in a way, if

someone said no, you wouldn't, but you don't assume they will say no...

HA So you are expecting yes, but its decency to ask?

yes yes (Interview 11)

Another participant described her view that compliance with a nursing care procedure was an indication of implied consent.

Most consent we do get from the patient even if not explicitly...quite implicitly.. you do something and they (the patient) lie there and let you do anything...some patients you can tell by their faces it's just "get on and do what you have to"... "I'm too ill" ...that's mostly how the work gets done. we do ask permission if it's invasive but a lot of the time, it's implicit...I think that happens a lot..we say I think it's a good idea to put a catheter in. They don't complain, so we do it...(Interview 9)

Many participants described how, in their view, patients give implied consent prior to nursing care procedures. Although the evidence is not detailed enough, there is little evidence that facilitating implied consent is an accurate description of the nurse patient interaction. Furthermore, given that many patients are uninformed about many nursing care procedures, and that opting out of care is difficult to do (as described in Chapter 5) it seems unlikely that implied consent is really obtained. Indeed, when questioned more closely, many participants expressed the view that this 'implied consent' may be more accurately described as compliance.

In one focus group discussion, participants addressed the extent to which consent may be implicit within the interaction between nurse and patient. They finally concluded that consent had really been compliance.

It can be implied, can't it? ... body language ... they take off their cardigan before you get to them it's implied that they gave consent.

H.A. Do you feel that is a consent?

We certainly take it as a consent

H.A. Is it? Is compliance consent? Did you mean compliance or did you mean something slightly different?

No no, I probably mean compliance. (Focus group 5)

Compliance, following a courteous request, does not necessarily amount to the patient's implied consent. The patient may be complying without consenting. There is an obvious theoretical difference between compliance and implied consent. Compliance entails submitting to the plan of another while consent requires an active authorisation.

However, in practice, it may be difficult to distinguish between the two concepts. Take for example, three patients who present themselves for vaccination. Patient X holds her arm out for vaccination out of mere compliance, without information and possibly under duress. Patient Y has had information but does not really want the vaccination. Patient Z has been informed and actively wants the vaccination. Only patient Z can be said to have given an implied consent to the vaccination. This is important because on practical terms, nurses must distinguish between the patient's (possibly unwilling) compliance and his or her implied consent. Failure to distinguish between the two will result in patient compliance – as in the example cited above – being mistaken for implied consent. One difficulty with the use of implied consent is that it places the onus of responsibility on the patient to register his dislike of the proposed action. In order to withhold his consent, the patient must complain or protest. If he fails to do so, he has implied his consent. However, failure to withhold consent may not indicate an implied consent. The patient may be uninformed, too ill, or compliant to register his objection.

Furthermore, in addition to the practical difficulties in distinguishing between the patient's implied consent and his compliance, there is evidence that some participants are unable to distinguish between the terms in theory. There is evidence that participants were uncertain of the meaning of the term 'implied consent'. Many nurses in this study used the term to describe consent, which had not been implied but had merely been assumed; that is not obtained.

There may be a fine line between what is an implied consent and what only an assumption of that consent. This is especially so if it is accepted that what amounts to an informed consent may constitute only minimal information, as argued in Chapter 1. One participant acknowledged this fine line distinction. She begins by describing what might be considered to

be an implied consent but then suggests that this 'consent' may have been assumed:

A lot of it is implied consent, by implication, non verbal...like if you give an IV (intravenous injection) they put their arm out. You pick up on that rather than anything formal. I think nurses are quite bad, they work on assumption, rather than anything direct. (Interview 20)

There are problems with the use of implied consent prior to nursing care procedures. Firstly, it might not actually be obtained. There are practical difficulties in distinguishing what is an implied consent and what is compliance. Nurses may proceed with a care procedure when they assume there is an implied consent. In reality the patient has complied. He has not given an implied consent. Kennedy and Grubb (2000) (p591) refer to implied consent as a form of estoppel. They argue that "a patient will be estopped from denying that he consented to a procedure" because of the difficulty in interpreting what is and what is not an implied consent.

Secondly, this situation is exacerbated by nurses' lack of clarity concerning the differences between the two. This is not to say that there should be no role for implied consent prior to nursing care procedures. Implied consent can be an appropriate way to obtain consent prior to nursing care procedures. It takes into account the relationship with the patient, the nature of nursing, ongoing information giving and assessment. However it is important that there is clarity in the terms that are used to describe practice and that where implied consent is appropriate it is actually obtained. The way in which implied consent can be facilitated prior to nursing care procedures will be examined in Chapter 7.

4.5 Consent is often not obtained because of patient compliance

Many participants did not claim that the patient's consent had been implied prior to nursing care procedures. Instead they suggested that one reason for assuming consent prior to nursing care procedures was that patients are generally compliant. In view of this anticipated compliance, participants acknowledged that they failed to seek consent because they could proceed without it without any practical difficulty. The patient was generally compliant and presented no objection to the procedure. All data relating to patient compliance was exploratory; it did not relate to a specific incident in practice.

Many participants had observed that patients become compliant when they enter a hospital situation. One focus group described:

...Patients' behaviour changes when they're in a hospital environment. For instance, immediately they get into their nighties and get into bed as if they're ill, so perhaps patients in a way expect certain behaviour.

They expect nurses to be respected - they respect nurses and they expect them to be in a role of authority - we know what we're doing and what might be best for them and they might then feel that they must be compliant because we know best. (Focus group 5)

One group of participants identified various examples of this compliance:

You do someone's temperature. you look at the chart and someone's already done the observations...they don't say...

I've been in nursing ten years - only twice has a patient refused to be washed by me in hospital (male nurse)

I remember when I was a first warder there was a patient who worked in the city - he was in his pyjamas I had to give him a suppository. A contrast to when he was in a suit to when he was a patient and I could pretty well do whatever I liked to him.

(Focus group 1)

One participant in a focus group related her own experience of being a patient as an example of patient compliance:

People take on role of the patient. We were saying - if you yourself go to the doctor you may have some questions, but you go in and see the doctor. You come home and think I haven't asked him any questions I'd say I'd do that normally, but you don't

(Focus group 4)

Another participant added:

If they are not strong enough they'll accept - go with the flow ...when you're in the situation - I've been a patient - you just roll with it (Focus group 4)

One participant in a critical incident interview suggested that patient compliance seemed to negate the need to seek consent. She described:

We generally say "we've got to do this, we've got to do that... you can have a bath now". They don't complain, the majority don't say anything and will let you do virtually anything, let medical students watch...student nurses. Everyone seems very compliant, which is maybe why no one searches for consent very much. If you expect them to accept what you are doing... you don't often get people...when someone does turn round and say "excuse me, I don't want this, or why are you doing this?" It can sometimes be...just wakes you up every now and again, you're tired, you are just wandering round saying 'you need this, you must have this' people don't complain, people don't ask too many questions either. (Incident 4)

It was remarked that compliance was imposed by restraints of time, routine and convenience. One group of participants discussed:

Sometimes you want to do it there and then for your convenience - not the patient...

That's a big issue.

But the best interests of the rest of the patients. You can't keep on changing the schedule because someone says no, you've got ten others...

(Focus group 4)

The reasons for this were discussed:

The ward is a social place. It has its rules. Meals come at a certain time. If you're lucky...*

Practicalities have to override personal freedom ...

Rules in society - if a patient doesn't have a bath ... does that person actually have the right to say no in terms of the people around you - impinge on others?

(Focus group 4)

Patient compliance with hospital routine has been observed in early and more recent studies, for example, (Skipper 1965), (McCormack 1998) and (Waterworth & Luker 1990). However the extent to which patients willingly comply with hospital routines and procedures remains unclear. Waterworth and Luker, (1990) interviewed a small sample of patients about their involvement in nursing care. They found that patients were primarily concerned about fitting into ward routine and 'toeing the line' and that this was more important to them than participation in decision making. It is unclear whether patients felt obliged to 'toe the line' because of the influences of the hospital environment or whether they, as patients, were by nature compliant. It is unclear whether patients *wanted* to 'toe the line' or whether they merely felt obliged and restrained to do so. However the possibility that patients feel compelled to comply with care procedures further reinforces the differences between implied consent and compliance.

One participant in the present study questioned whether patient compliance so often observed was entered into willingly by patients. She commented on the pressure she perceived patients are under to comply.

I think we try and get patients to fit into your little plan for the day and if they don't, it throws you completely. You've got medication to do at 8 am you don't sit down and explain what they are and what they are for, you just give them out and expect them to take them. Where I trained, it was old fashioned, being a student, no one ever asked your opinion, if a doctor said that his patient is going to have a procedure, you made sure the pt had the procedure. When the doctor came back the next morning you were going to look like an idiot if he hadn't. You didn't dare say "but the patient didn't want it" you just did it, however unpleasant for the pt. otherwise you'd be made to feel an inch high if it wasn't done. It was a lot of trying to make yourself acceptable. Patients are temporary they come and go you have got to work there. (Interview 2)

In a focus group, one group of participants felt that patients are passive and vulnerable:

Because you didn't ask the question you normally would have done. You're in a situation - you're not in control of ...

Someone else dictates to you what time you're going to get up. What time you're going to bed, have breakfast.

(Focus group 4)

Participants in this study, as in others, observed a culture of patient compliance and identified some of the factors, which may contribute towards it. Clearly, compliance is a necessary component in the running of any organisation. An element of compliance may be a necessary state of those entering any institution. There are social norms and rules that have to be observed for any institution to function. This was observed by some participants.

However, total compliance undermines the principles of informed consent. It is uncertain whether those who are compliant, accept this role happily. They may feel compelled to adopt this role. It is possible that patients are compliant even when they have an objection to the proposed care. Patient compliance may be therefore misinterpreted as implied consent as described above. Participant's response to patients who were not compliant is discussed in Chapter 5.. Furthermore, some participants described how nurses disregard any consideration of consent because of the patient's observed or anticipated compliance with the procedure. Patient compliance was identified as a reason for not seeking consent; a pragmatic response to patients' observed behaviour. The way in which nurses should proceed when patients are compliant is discussed in Chapter 7.

4.6 Consent is not obtained because patients do not expect it.

Closely related to the concept of compliance is the suggestion made by many participants that consent is not obtained prior to many nursing care procedures because patients do not expect to be consulted at every stage of care. They felt consent to be unnecessary prior to many nursing care procedures:

You presume you have consent, you don't specifically ask for it. You say "I am going to redress your wound because it needs changing" some things, like taking out stitches, after so many days, your stitches need to come out. We don't say " can I take them out?"...may be it's because....after a number of days, it's optimum to take them out, and from a wound point of view, it's best for the patient and you take it for granted that the patient realises that you have their best interests and you have the knowledge..

H.A. It's taken for granted from the nurses point of view, do you think it is taken for granted from the patients point of view?

I think it is ..they do trust..one patient, I was taking out his clips and he said "I just let you get on with it, you know what you are doing. I'm not one of these who wants to be told everything.. (Interview 28)

One focus group discussion explored the necessity of consent prior to nursing care procedures:

In some situations patients... they get infuriated if a nurse asks them everything they might have just come back from theatre and they are having to concentrate ...very unwell in pain, the last thing they want is someone to say . . .

And I think the patient would get very irritated . . . "don't you know what you're doing!"

Most of the time, patients don't expect to be asked. They take on a passive role . . . if you keep on asking questions . . . they'd say what's wrong they'd think you didn't know what you were doing!

(Focus group 4)

Another group of participants expressed similar views to above. They felt that the trust implicit within the nurse-patient relationship negated the need for consent.

Is it always a problem ...? I mean eventually you have a trusting relationship with the patient .. if you inform him, the patient should be able to say at the time..

It's traditionally thought that nursing practice is actually beneficial, that they actually want you to do that...

You don't want to subject patients ... you first don't want to overstep that trust... the nurse- patient ... the relationship....

(Focus group 2)

The participants cited above are suggesting that there are some procedures prior to which consent is unnecessary. They cite trust in the nurse patient relationship as an inherent factor in the necessity to obtain consent. Another group of participants took this argument further. They felt that the nurse patient relationship would be threatened by the introduction of consent procedures. They felt that trust in the nurse patient relationship was more important than

consent prior to a nursing care procedure:

It's trust and partnership - more than formal consent

I don't seize with this idea of consent - and nursing the whole idea ... perhaps invasive procedures - to an extent- catheters, fair enough...

It's taking away a lot from nursing.

Quite

*For us it's getting in the way of getting to the patient. You're trained as a nurse
Getting in the way of the relationship and trust making it formal. It can't be too
formal. It's is such an intimate relationship anyway.*

(Focus group 2)

The participants are suggesting that good communication in a trusting relationship should negate the need to obtain consent. This discussion is indicative of a lack of understanding of the informed consent process within nursing. Clearly, 'formal' consent procedures may be inappropriate to many nurse patient interactions. However, these participants viewed gaining consent and the partnership between nurse and patient as mutually exclusive. They did not consider that consent could be obtained verbally or implied and that this would be facilitated by a good relationship between nurse and patient in which the patient is adequately informed and feels happy to say no.

Although the arguments rehearsed by this group of participants might appear extreme, they reflect those rehearsed in Chapter 1. The purpose of consent is to protect patient autonomy and to protect the nurse from the potential charge of battery. If the nursing care procedures does not threaten the autonomy of the patient, consent is not required. To insist on consent prior to these care procedures is therefore inappropriate.

4.7 Is there a web of expectation about health care delivery?

Engelhardt (1986) argues that many of the agreements for contact between health care professional and patient are undertaken through a culture of expectation that exists within the healthcare setting. He describes the web of expectation that exists within health care:

In health care men and women create a web of expectations and permissions through agreements to be touched and explored by others, through commitments to confidentiality and the keeping of special trusts and by fashioning common understandings of goals to be pursued... (p250)

Participants' accounts of consent prior to nursing care in this study (cited above) also suggest that a concept of a web of expectation exists that negates the requirement for consent prior to certain nursing care procedures. The web of expectation is a different concept to that of compliance. The web of expectation indicates a willingness or acceptance on the part of the patient for health care provision. This acceptance is not necessarily a component of compliance. The existence of this web of expectation is suggested in the studies of patient participation.

Biley (1992) examined patient participation in the nursing care of surgical patients in the preoperative period. Acknowledging the tentative nature of the conclusions following interviews with eight patients, He described some of the factors which affected the patient's ability and willingness to participate in care. He found that patients were keen to participate in care if they were sufficiently well informed and if the constraints of the institution allowed participation. However, not all patients were willing to participate. These patients expected nursing care to be administered without their participation. Such care can be said to be administered within a 'web of expectation'.

In a small qualitative study, Waterworth and Luker (1990) found that patients were primarily concerned about fitting into ward routine and 'toeing the line' and that this was more important to them than participation in decision making. In a later study, Caress (1997) examined whether patients wanted to be involved in decision making concerning nursing care procedures. Caress found that the majority of patients preferred to take a passive role in the decision making process. Trust in the health care professional and lack of nursing knowledge were cited as reasons for this.

These studies in addition to the data cited in the section above endorse Engelhardt's argument that a 'web of expectation' exists in the delivery of health care. The web of expectation needs to be compared with the term implied consent. The two concepts are similar but essentially different. When the patient gives his or her implied consent, it has been argued, he or she is

actually consenting. The consent is expressed by implication. When a care procedure falls within the web of expectation about health care delivery, the components of consent are not necessarily present. The patient 'accepts' rather than 'consents' to the procedure. In practice, the two concepts might be indistinguishable from one another. The differences might seem spurious. However it is important that the differences are acknowledged if conceptual clarity is required.

4.8 The web of expectation does not apply to all nursing care procedures.

Engelhardt is clear that there are limitations concerning the boundaries of these expectations and that these boundaries can be negotiated through communication. He continues:

as total commitments are rare in everyday life, the same is true in health care. Few patients commit themselves without reservation to the care of the physician. (p250)

That the 'web of expectation' does not cover all aspects of nursing care was identified by Brooking (1989) in a study of patient participation. In this study, patient participation was explored from the perspective of nurses, patients and relatives in a questionnaire study. Brooking found that nurses generally had a positive attitude towards patient participation and claimed to facilitate this interaction. They did not feel that the 'web of expectation' (although this term was not used by Brooking) covered the administration of all nursing care. Neither did the patients who were involved with the study. Patients expressed the desire to participate in their care although few seemed to have experienced this. The finding that both nurses and patients expressed the desire for patient participation in care suggests that a 'web of expectation' is not a comprehensive concept that negates the need for consent prior to nursing care procedures.

If the concept of a web of expectation is accepted, it is essential that nurses recognise which care procedures are covered by the 'web of expectation', and which are not. Theoretically, this may be achieved through a process of assessment, as the nurse builds a relationship with the patient. One participant described how he could assess whether a patient wanted to be informed:

not every patient wants to know. You can tell if a patient wants to know, if you talk to them and you get one word answers, and they don't show any interest. They probably don't want to know..but you should still ask if it's OK. You don't really think about it.

They say "come in and do what you have to do"... just washing a patient. I would never wash someone who said they don't want it. You must ask them if they mind... (

Interview 9)

Another participant expressed the view that it was possible that the amount of information required by the patient can be assessed by the nurse, although he does not state exactly how:

H.A. Is it hard to know what patients do want to know?

It comes back to assessment and gearing things to what a patient wants to know..in talking to people it's quite easy to pick that up, what they want to know..

H.A. With experience?

Yes, it does come from experience (Interview 23)

The web of expectation clearly does not apply to all nursing care procedures but it may justify proceeding with nursing care procedures following minimal or no explanation if the patient has no objection and anticipates the procedure. However, it is crucial that nurses can identify those procedures which lie within the web of expectation and those which do not. If nurses are unable to identify those procedures accurately, they threaten to infringe the autonomy of the patient. The following two incidents describe how nurses misjudged the boundaries of the web of expectation.

Two critical incidents reinforce the argument that the web of expectation does not extend to all nursing care procedures. In the following incidents, participants misjudged the care that could be administered following minimal or no explanation.

In the first incident, a participant described a situation which he felt was badly managed. The participant had been asked to catheterise a patient who was going for surgery. He discovered that neither he nor the patient were aware of the reasons for catheterisation.

A patient who...he was another nurse's patient. He came up to the ward for abdominal surgery. I was asked to catheterise him. I went to him with a tray and said "I need to catheterise you, do you know what you are having this for?" he said "no, I don't know

what it's for". He was in his middle 30s. He wasn't my patient, I had to go out and find out why he was being catheterised. The guy was having surgery and wasn't informed about what was happening to him. It was just mentioned by one of the doctors "X (nurse's name) can you catheterise this patient?" "yes no problem". I didn't feel that was very good. I think he should have been told what was happening...(Interview 4)

The participant was concerned to establish, from a professional point of view, why the patient was having the catheter view:

I wanted to know why I was putting it in more than anything, so I had to check it and I went back and explained it to him... so that was one that wasn't handled very well, not as well as possible (Interview 4)

It is interesting to note that the participant was concerned about the provision of information given to the patient rather than the opportunity to consent. In the participant's view, had the information been more sensitively given, the situation may have been better. When we discussed how the incident may have been managed, optimally, the participant suggested improvement in information giving; he did not suggest that consent should have been sought.

It could have been discussed by the nurse, the whole process, "this is going to happen, you've got to have surgery, we've got to do this, we'd like to do that" and just give a bit of preoperative advice...just let him know what's happening. It's daunting if you are in a little room, waiting to go out on a trolley, you don't know what is going to happen... when they're taking your blood, all that sort of stuff. (Incident 4)

In the second incident, a nursing care procedure was carried out on a patient had not been informed about it. The patient objected to the unannounced administration of care.

Two nurses once presumed they had a patient's consent...they went to move a patient who shouted out, when I went to see why she was shouting, she hadn't been told she was going to be moved...she just shouted "what are you doing" she was a little bit confused. The nurses, when I questioned them, were quite rightly helping the patient change her position, which she needed to do, but didn't think to tell her...it was a good episode for them to reflect on their practice....(Interview 23)

Again, the language used to describe the incident indicates that the participant felt that the patient should have been informed (told) about the forthcoming procedure, rather than been asked for her consent. The participant describes how this incident was utilised as a point of reflection in the clinical environment:

They used it as a turning point. it brought it home and their practice was addressed. Sometimes people don't realise that they have got into an automatic mode of working, coming to work, dealing with people, you forget they are human beings.

H.A. What should happen in that situation?

You should explain what you are going to do, and why, and try and gain a consent to the manoeuvre. If they blatantly refuse, perhaps someone else could have a go, or try a different tack, come back in a few minutes...find out why they don't want to do what you want them to do. (Interview 23)

These two incidents illustrate that the web of expectation cannot always be used to justify proceeding without the consent of the patient. Not all nursing care procedures fall inside this web. Furthermore, they demonstrate how it is possible to misjudge the patient's web of expectation. However there is evidence from the data presented in this thesis and the studies concerning patient participation that a 'web of expectation' does exist in health care. The web of expectation may be a useful concept for understanding the circumstances in which it is appropriate to proceed with nursing care procedures following minimal or no explanation to the patient. Not all patients want to be involved in all aspects of decision making. They may be irritated if asked to do so. It is argued that it is justifiable to proceed without consent if the procedure falls under the patient's 'web of expectation' of care delivery. However many patients do want to be involved in many aspects of decision making. Failure to accurately identify those procedures which lie within the patient's web of expectation will result in an infringement of patient autonomy, and subsequently a failure to comply with the principles of informed consent. While the web of expectation may provide a theoretical justification for proceeding without the consent of the patient, in practice, the web might be difficult to identify.

Interim summary

Many participants described how care procedures were carried out following minimal or no explanation to the patient. It is argued that neither patient compliance or unsubstantiated claims

that consent has been implied can be used to justify proceeding with a nursing care procedure without the patient's consent, when consent is required. However, there is evidence that a web of expectation about health care delivery exists. This expectation may negate the need for consent prior to some nursing care procedures. Consent is not required prior to those procedures which fall within the patient's web of expectation. However, if the web of expectation is used to justify proceeding with nursing care procedures without the consent of the patient, it is essential that those procedures undertaken without the patient's consent really do fall within this web. Proceeding with a nursing care procedure without consent on the pretext that it falls into the patient's web of expectation runs the risk that the importance of this procedure to the patient has been misjudged. Such cases would lead to infringement of patient autonomy.

4.9 Information is given prior to *some* nursing care procedures.

There is evidence that some care procedures are accompanied by information giving. Participants in the focus group discussions expressed the view that information is given to patients prior to (certain) nursing care procedures. One group discussed:

I don't think you ever go in and not say anything... you never don't say anything you would always have a conversation beforehand ... even if it's I'm just going to do your blood pressure you don't you never go in and just not speak i.e. do something to them without speaking I don't think you do anyway.

A lot in to do with discussion. ...you usually do it through explanation. You say is that all right?

I think one way or another we do get consent - you say I'm just going to do your blood pressure.

I think if you were going to run about and say "is it all right if I do your blood pressure...?". I think you'd be there all day

(Focus group 4)

There is evidence that information giving is selective. Participants in the focus group were able to identify certain procedures, which are accompanied by additional information giving. These tended to be invasive procedures or those involving intimate bodily contact. Participants

generally felt that the more invasive a procedure, the more information was given and the greater the need for consent. Excerpts from all discussions are given below

(information is given prior to) *things which will actually be unpleasant . . . injections.*

(Focus group 1)

There are other procedures like vein puncture - I always check with the patient before I take blood. Explain why and how I'm going to do it.

Female catheterisation. You don't just go up, you explain it that ok with you.

(Focus group 2)

The examination of female patients by a male nurse...

When you're doing something quite intimate with a patient you should really be getting their consent - like for an enema or suppository...

They accept that you examine them because you have to.

(Focus group 3)

(nursing care that) involves the patient's sexuality ..Invasive...

naso gastric feeding. Injections...

Injections

(Focus group 4)

The more invasive it is the more you need to be explicit by consent, isn't it? Less invasive, less, less explicit.

H.A. So there's a continuum perhaps, is there?

Yes, you would never catheterise someone without getting explicit consent.

You'd never give an enema, injection ...

But you don't ask when you give a four hourly aspirin. You don't say, can I administer this aspirin?

(Focus group 5)

There was agreement among participants in the focus groups that the more invasive or intimate the procedure, the more focus should be given to information giving (or consent gaining) prior to this procedure. The terms information giving and consent are used interchangeably throughout the discussion. The participants were able to produce a deductive list of those procedures prior to which they felt consent to be necessary. The list was found to be consistent throughout all focus groups.

Participants in this study demonstrated the same reasoning as identified in the literature about informed consent. That is, consent is required only prior to invasive, risky or other procedures that can be predefined. They did not consider that consent might be required prior to procedures which might be threatening in some way to the patient. They did not express recognition that patient autonomy can be breached by the most benign nursing care procedure or that those procedures requiring consent should be assessed on an individual patient basis.

4.10 Nurses focus on information giving; not consent seeking

Furthermore, closer examination of participants' approach to information giving indicates a perception that the patient has a right to information as opposed to a right to information to facilitate his or her consent. This is illustrated by the following participant's observation:

You tell the patient: 'these are the options available... maybe a subcutaneous pump .. or an intravenous line' but you wouldn't necessarily get a consent- you go to the drug cupboard ... They agree and then you come back and relay the information.

(Focus group 2)

Another participant described:

We do ask... we go up, and say "I think it would be a good idea if we popped a catheter in, do you mind? We explain why, that it may only need a couple of days. When the patient is awake, I will always explain what I'm about to do... how I'm going to do it, if it will be uncomfortable. I would never go in and just do it ..."

(Interview 9)

The participant is adamant that she would not carry out the procedure in question until she had informed the patient about it. In her view, the patient has a right to receive information about the proposed care. She does not indicate whether, in her view, the patient has a right to information about alternative options, which would constitute a necessary component of an informed consent. Failure to give alternative options provides evidence that a valid consent has not been sought. Three participants also identified that this was so. One participant described how she gave information about the procedure but not about alternatives.

The most unpleasant thing you can do is a naso-gastric tube...I always ask, but if I am honest, it is not a case that you have an option really, it's just said that "you need an ng tube for such and such a reason and I'm going to do that now" and I explain the procedure... what I don't do is give them the option of what will happen if they don't have the tube. Being honest, I don't say... "this is what will happen if you don't have the tube..." I might if they say "I don't want it done", but I don't offer it automatically.

H.A. Is the focus on giving information? (which is limited to giving information about the intended procedure only)

Yes that is completely right, it's not on giving consent.

(Interview 19)

A second and third participant described how although information is given to patients, the alternative options were not given.

On the whole if you explain to patients... doctors tend to explain in a way that there is no option....not just doctors... they - elderly people tend to think that what we say is best...say with incontinence, catheters, we say "we'll do it this way.... and when you are a bit better...it will come out. (Interview 22)

The third participant described:

Blood transfusions, people don't get asked particularly, they just get told...it gets

prescribed. I say you have a need for a transfusion. They say; 'do I have to ?' I explain why and that's as far as it goes. Blood comes up and you do blood observations and that is it. ...I explain more about blood than a normal IV, but it's still not like getting consent because you are not explaining there are alternatives or in any great detail what it's for. "You've got a low iron" - this means nothing to a normal patient.. They think you are a nurse, get on with it. Even when it's got potassium in it you just say 'it's fluid'. Often they think 'this is water so I can't drink anything else.' You try and explain...but they think they don't have a choice., while it's up they don't drink, when it comes down they can. A lot of patients don't know they can ask. They don't even think they can ask. It doesn't occur to them to ask. I guess it's easier for doctors / nurses to go along with that. It's a lot easier if you can do everything you need to do to a patient. (Interview 2)

One reason for this approach was offered by a participant. In her view, it is easier to carry out care procedures without having to obtain consent. An explanation is one sided. It does not necessarily entail an agreement or a consent. This view was reinforced by another participant who described:

I find it a lot easier to explain to the patient what I am going to do and not actually say " do you mind?" I presume they do want their wire / catheter / venflon out. That aspect of consent I do find easier to forget about.. I think it's acceptable as long as you have explained the procedure, warn that it may hurt, as long as they know what to expect. I would presume they would say " that is going to be dreadful". So I don't formally ask. (Interview 26)

Another participant described how information is given to patients, but not necessarily prior to commencing the procedure. Information was given at the same time as the procedure is undertaken, reinforcing the perception that it is the information per se, rather than the patient's opportunity to consent, which is at issue.

Catheterisation...you explain what is going on, sometimes they don't understand, you get into a habit where you explain automatically as you go along... (Interview 8)

The participant indicated that this style of information giving is well entrenched in nursing practice:

You become formed as a nurse to do this... in circumstances where the patient is unconscious, he's unable. It's like you automatically talk to a patient who has died... "I'm going to turn you over now" it's automatic...catheters we do quite frequently, I've never seen it where it hasn't been explained properly...(Interview 8)

There is evidence that some nurses do give information to patients prior to or during certain nursing care procedures. However, many of these reports are vague; there are not recounted as critical incidents. They are recounted as examples of what nurses say they do. However, many nurses expressed the view that the patient has a right to information about proposed care. It is noticeable that there is a philosophy within nursing that a patient should be informed about certain aspects of the care he receives; in the same way that an individual is entitled to know the components of his phone bill, but he has to pay it none the less. The patient has a right to be informed about the proposed care, but he will receive it none-the-less. Nurses in this study did not express the view that patients have a right to receive information about their care, which may facilitate his consent to that care.

One participant identified critical happenings, which clearly demonstrated that information giving is not synonymous with consent seeking. The participant was concerned that patients are not told about alternative options to the intended plan of care:

I suppose when we do things such as putting drips up, we explain it as we do it, as opposed to saying is it all right if we do this...? We put G.T.N. up (glycerol trinitrate) before a certain procedure and this can often cause a drop in blood pressure and headache, and the doctors here use it, but not all doctors use it in all centres, there are other alternatives. Like tablets, which don't have such a dramatic effect. We explain to the patient, we don't just sit the pt down and say "you need this drip, these are the side effects and benefits.." you explain to the patient as you are doing it, that we will be checking their blood pressure as it can cause a drop in blood pressure and they may well get a headache, but we can give paracetamol...I've been looking at G.T.N. because of the time aspect in setting up an infusion and I know there are tablets which don't have such side effects. I have literature, the tablets aren't for licensed use yet...so it varies....it's not cut and dried...It would be very difficult to know what to say to a patient if he said "is there anything else I could have?"...That's why I'm quite keen to look into it. ...it is something that is done in a rush. We are trying to set up a

preadmission clinic where we could talk to patients about the procedures... They may have had more time to think about it.

(Interview 21)

The participant had identified happenings in clinical practice which clearly illustrates that information giving is not the same as consent seeking. This difference was acknowledged by another participant. However, he did not consider consent seeking to be a common part of nursing practice.

If you give them information that doesn't mean they are going to consent to it. For someone to consent they actually need to know the information, what you are going to do, but they don't have to consent to it. I'm trying to think when else we get consent from patients. Catheterisation was my main thought, because as an invasive procedure we do. For an injection we don't really get consent.

(Interview 4)

There is evidence that information giving accompanies those nursing care procedures which had been pre-identified by the care giver as significant to the patient. Furthermore, there is evidence that the information accompanying these care procedures is given not to facilitate consent but because of a belief that (at certain times) a patient has a right to information. The focus is on information giving not seeking the patient's consent.

4.11 Information giving as a tool for achieving compliance

Further examination of the data indicates one reason why participants felt information giving to be important. They felt that information giving might facilitate the patient's compliance with the care procedure.

In an earlier section, participants described how it was possible to disregard consent because of patient compliance. In this section, there is evidence that some participants regarded information giving as important means of ensuring compliance with a care regime.

Participants in the focus groups expressed the view that information was given in a way that assumed compliance. They perceived that it was therefore difficult for patients to refuse. One focus group discussed:

H.A. And is the opportunity there to say no, do you think?

Maybe the way we phrase our questions doesn't give them a chance "Can I take your blood pressure?. Yes. They feel they can't say no. (Focus group 5)

It was widely held that patients are informed in a way that will ensure their compliance. One discussion ran as follows:

You can say: "You can have a bath now. I'd do that at such & such a time because it's the only time available. But the question assumes that they want a bath...

I always ask - but it's how you ask

There's a way to ask question so that you assume the answer is yes.

We cajole "this is a good time to do it". You use a lot of closed questions...is it all right? I'm first going toYou question them, but give them the answer. (Focus group 4)

Another discussion ran as follows:

In relation to dressings: the question assumes that they will have the dressing done

You say "is it OK if I do your dressings now?"

Consent is only really about the time (Focus group1)

And another:

We don't explain that there is a choice. We say why we are going to do it.

We don't say that they don't have to consent to it. We don't say we can do this or we can do that.

Pain control - we can control your pain, but we don't give a choice

(Focus group 3)

One participant identified how information given may be weighted towards the positive aspect of care:

When you explain you don't concentrate much on the negative side of things.

One group discussion gave rise to the suggestion that this style of informing may be exaggerated during busy times.

But you have to be careful how you word thingssometimes you can say things if you're in a hurry...for example "If we don't do this, this is going to happen". It's almost as if - not threatening but shock tactics, coercing...

Shock tactics, intimidation .

Can be (Focus group 4)

A patient quoted by a participant commented that nurses' intention to carry out care procedures seemed to be firmly resolved; that it did not seem to be dependent on the patient's authorisation.

I've actually heard patients say in a joking fashion when you've gone up them and said I'm going to do your blood pressure, is that OK? And they've said "well you're going to do it anyway aren't you". I've heard that said on occasions. The patients are taking it as well that's what I'm here for sort of thing. (Focus group 5)

One participant in a critical incident interview described how information is given to achieve compliance:

I suppose with medication, we are educating patients, because they will go home on them .It's about compliance. You get better compliance if patients understand what they are taking and why. With medication, although you can be repetitive, it's more important to be repetitive..make sure the patient understands what they are taking

H.A. Is information giving in that case more for compliance than consent?

Compliance and consent, but I suppose they don't feel in a position to refuse, they don't like to rock the boat... (Interview 23)

Another participant described how she gave information to patients as a means of ensuring their compliance with an important care regime:

Patients who have cardiac catheters and after the procedure has been carried out they have puncture sites in the femoral vein.... patients are always on flat bedrest after the procedure. I have had patients refuse to stay flat. I explain why they must stay flat, that they increase the risk that the site may bleed. They think that if they can't see blood. So they sit up and they do have a big bleed. I always give people a detailed account of why they need to stay flat, that if they move around they will have a big haemorrhage. I threaten people with what might happen....it's necessary to make them stay still. Their knowledge of what might happen is zero.

H.A. So are you using information as a way of getting compliance?

Yes...even from not messing with dressings and things...

H.A. So is it less about consent and more about compliance? Would that be fair?

I think it is....I mean you want the patient to do everything right so that their management goes right. They ultimately want their management to go right, to be successful. You both have the same goal. You give information to make them compliant. (Interview 26)

The participant illustrated how, in her view, information was used as a means to ensure compliance with another example. She demonstrated this by acknowledging the problems caused when a patient cannot be reassured by the provision of information.

One other thing is that I find with gaining consent- putting a catheter in, patients who are frightened or intellectually slow, it's very difficult to say why you are doing

something. Often you only get as far as what you are going to do and how you are going to do it. Some frightened patients can't take things in. You don't get an informed consent, you only get an informed compliance. These frightened patient or slow patients are the ones who may pull their catheter out because they don't know what's what. (Interview 26)

Another participant described how more information may be offered to the patient if there is a greater need for their co-operation-

With feeding tubes you look at consent, but I think it is from the point of co-operation. If you don't have co-operation...you need them to do what you want them to do otherwise you can't pass the tube... a lot of co-operative patients who have them passed time and time again. You explain. Usually the dietician is involved and will explain as well, the need for having a feeding tube. as the nurse, you go along and say "I'm going to pass the feeding tube, this is what it looks like, this is what you have to do, you have to swallow the tube when I say". You explain the procedure and you get their consent, for having the procedure done...maybe we take it for granted...most patients...they know they need I.V. antibiotics and we assume consent.

H.A. It's interesting that we assume for IV antibiotics but not naso-gastric feed?

It is because we need their co-operation... any type of wound care... you explain what material you are putting on the wound and why...(Interview 28)

Another participant described how, in her view, giving information to patients was a way of promoting their consent to the intended care (as opposed to allowing them to make a decision about the intended care). She described:

You develop a relationship and in a relationship you have communication...it's about getting to know someone, they get to know you and that's how we exchange information and find out what people's needs are. Thus they get involved and they are more likely to be consenting to what is happening. (Interview 18)

Another participant identified that information forms a crucial role in assisting the patient in coping with the procedure.

This is how nurses are trained ...its just that. Doing a dressing, we explain as we go along, beforehand, they get to know it any way, but if someone is able to understand. so you have the information that it might leak ... you give them info for their own coping really... there is something violating their body, something alien even if it's something minor... they need to know what is going on so that they can gain control... (Interview 8)

While it is well established that information giving plays a contributory role in many aspects of patient care, (Hayward 1975), (Wilson-Barnett 1979), it must be acknowledged that information giving is clearly not synonymous with consent seeking.

The use of information to facilitate patient compliance as opposed to consent was identified by McCormack (1998) who examined the discharge process of patients in elderly care units through conversational analysis. He found much evidence of information giving to patients by nurses concerning discharge planning. He commented:

One of the surprising aspects of the data is the extent of information giving and teaching that takes place between the nurses and patients (p210)

However, despite this focus on information giving, McCormack found that patients were not correspondingly increasingly empowered to take their own decisions. Instead, nurses used information giving as a means to ensure that decisions that had already been made were enforced. McCormack's observation support the findings of this study. That is, information can be, and is used by nurses as a tool to achieve compliance. McCormack commented:

The lack of a clear framework in which such information was contained and the dominant role of professionals in decision making resulted in such information acting as another form of control that served to reinforce the decisions already made by professionals, rather than as a means of enabling decision making by patients themselves" (p300)

Similarly, Levy (1999b) who found that midwives 'edited' the information given to women in an attempt to steer them towards decisions that were considered to be beneficial. She referred to this process as 'protective steering'. Clearly, it would be unacceptable for the midwife to

withhold advising the patient about the preferred course of action. However, there may be a fine line between using information giving merely to reinforce the implementation of a decision that had already been made and allowing the patient some choice in that decision making process. The use of information giving to reinforce and implement decisions that had already been decided upon by health care staff is discussed in further detail in Chapter 5. However, at this early stage in the presentation of data there is evidence that information is used to promote compliance rather than to facilitate patient choice and consent.

4.12 Patients are expected to opt out of nursing care

Despite this emphasis on compliance, many participants felt that the responsibility lay with the patient to opt out of care. One group of participants felt that the patient could opt out of nursing care should he wish to do so.

But you say "are you ready for your bath yet?" Would you like a bath now?

If they don't want one, they will tell you

(Focus group 4)

Another group of participants felt that patients were able to say no.

Yes. They often say I'm doing something at the moment, can you come back later, or I'm just going for a fag or something and we'll say OK we'll do it later. They don't always say yes OK.

(Focus group 5)

Many participants reported that patients were often asked whether they minded a certain procedure being carried out. This should assist the 'opting out' process. One group of participants described:

But I think you would seek a verbal consent anyway ... "is it alright if ...?"

H.A. You wouldn't rely on the implied consent....?

You don't tend to say, can I do your blood pressure ... sometimes you do, but other times you'll just say, I've come to do your blood pressure and they take their cardigan off.

It implies somebody's consent. If the opportunity is there to say no, then they don't take the opportunity...

(Focus group 5)

The group described how patients are asked whether they mind a particular nursing care being carried out. They discuss whether this is consent seeking or a basic courtesy:

But actually, you do it (verbal consent) all the time, because if you're going to give someone a bed bath, you say is it OK? and if they say no, you leave them alone, you don't say, well

I firmly believe that patients should be asked everything. I don't mean it has to be, will you give your consent?, but I think, as X said, is it OK?

And that doesn't take time to do that.

If you go back to nursing training, you're meant to always inform the patient of what you're going to do and why you're going to do it so they still have the option of saying no.

A lot of it is basic courtesy as well.

(Focus group 5)

The group participants discussed whether a courteous enquiry of the patient whether a nursing care procedure could be undertaken may amount to a consent.

Hopefully, you always show courtesy, but you are not always explicit about asking for consent.

But to be courteous, if we sort of pick up somebody and wash their arm, you say "can I wash your arm?"

But is that consent though? they can say no, it isn't alright.

What if somebody lets you wash them every morning and you've been washing them every morning for two weeks, do you go in the next day and say, do you want a wash or do you go in and say what time do you want your wash.

(Focus group 5)

Although many participants acknowledged that information was used to achieve compliance, others expressed the belief that patients could and should opt out of the care they did not wish. The extent to which a courteous enquiry "do you mind" enables a patient to opt out of care depends on whether the patient is informed enough about the intended procedure and feels able to refuse. The extent to which patient are able to opt out of care they do not wish to receive is debated extensively in the Chapter 5.

4.13 Is consent obtained in nursing when it is required?

Principle: The nurse should obtain the patient's consent when to proceed without consent would threaten a patient's autonomy. The approach to seeking consent should be patient centred. The requirement to obtain consent should be determined by individual patient need as should the information given. The nurse should ensure that in these instances the consent is valid; that the patient is aware and informed about the procedure and free from coercive interference.

There is evidence that many nursing care procedures are carried out following minimal or no explanation to the patient; the patient's consent is not obtained prior to many nursing care procedures. The reasons offered for this are that patients are compliant, or that their consent has already somehow been implied, or that consent is unnecessary because the care procedure in question falls within the boundaries of the patient's 'web of expectation'.

While these justifications for proceeding without expressed consent are considered valid in principle, it is argued that nurses should be wary of proceeding without the patient's express consent because of the difficulties in determining what the patient really wants. This is discussed by Kennedy and Grubb (1994) (p589)

Without express agreement, no one may know what was in the patient's mind, but it may be thought appropriate to prevent him complaining after the event that he did not consent.

Given the margin of error for incorrect evaluations of the nature of compliance or what falls into this web of expectation for each patient, it is argued that nurses should be cautious about proceeding without the patient's express consent. In addition, while implied consent is an accepted form of seeking consent, it is essential to ensure that it is obtained and that it is not assumed. This is discussed in chapter 7.

While many aspects of nursing care were carried out without information, there is evidence that information is offered prior to certain predefined care procedures; those which were perceived by nurses as intimate or invasive nursing care procedures. None of the participants in this study identified that even the most benign nursing care might threaten the autonomy of an individual patient. Furthermore, the role of information giving is important here. There is evidence that importance was attached to information giving prior to these procedures because of the role of information in facilitating patient compliance rather than consent.

Consent prior to nursing care procedures may be a subtle concept and one that is difficult to detect. It is difficult for nurses to distinguish between the patient's implied consent and his or her compliance. It is difficult for nurses to assess how much information is required by patients prior to a procedure. However there is no evidence that the participants who were involved in this study were working with an understanding of the basic principles of consent. Participants were primarily concerned to administer care. Information, when it was given to patients, tended to be given for reasons other than facilitating the patient's consent to the care procedure.

Bullet points: How is consent obtained prior to nursing care procedures?

1. Nursing care is often carried out following minimal or no explanation to the patient
2. Nurses justify this by appealing to the concept of patient compliance, patient acceptance of a procedure or implied consent
3. It is argued that nurses should be wary of proceeding without the express consent of a patient.
4. Where information is given, it is given with the aim of achieving the patient's compliance rather than seeking his or her consent

5 CHAPTER 5: THE PATIENT WHO IS RELUCTANT OR REFUSES A NURSING CARE PROCEDURE

5.1 Data included in this chapter

In Chapter 4, patient compliance was frequently cited as a reason why consent prior to nursing care procedures was often not addressed. Participants described how information would be given prior to certain nursing care procedures in which the patient's compliance was not expected. The following section demonstrates that not all patients are compliant with nursing care procedures. The section describes how participants involved in the study manage care situations in which the patient is reluctant to accept or refuses nursing care procedures. The extent to which participants assess the validity of and manage the reluctance or refusal are examined.

Inductive analysis of 103 critical incidents identified 33 incidents in which the reluctance and refusal of nursing care procedures was the main happening within the incident. These data are reinforced by exploratory data contained in 15 units of analysis from the focus group discussion. This data provides evidence of how consent is addressed when the patient is reluctant or refuses nursing care. Some of these data are presented and discussed in this chapter.

In so far as is possible, critical incidents and focus group discussion episodes included in this section concern only those events in which the patient's refusal or reluctance is considered to be substantially autonomous; that is, where there is no evidence to suggest that the patient is unable to make his own decisions. Incidents and discussions in which there is reason to suspect that the patient is unable to make his own decisions are discussed in Chapter 6.

5.2 The patient who is initially reluctant to accept a nursing care procedure. The use of information.

Many participants gave evidence of patients who were initially reluctant to accept nursing care procedures, but who accepted the procedure once they had received further information at an appropriate time about the proposed care. Participants expressed the view that patient reluctance can be due to poor timing with which the procedure is introduced and also lack of information. This was addressed in one of the focus group discussions.

Sometimes it's timing. Catheterisation is not life and death it just may help . . . it's

just timing. We want to do it now . the patient has to take it on board straight away. carry on going back to him. Give him the option.

Ascertain why he's refusing. Perhaps he thinks there's a female nurse doing it . . . and he'd prefer a male - does he think it's going to cause him a lot of pain - explain things you can do to minimise the pain. It is embarrassment . . . You have to ? why he is refusing ? . . . and then try and address the issues. No one refuses something for the sake of it. You've got a reason behind it.

(Focus group 4)

In the critical incidents, participants gave detailed accounts of incidents in which patients were reluctant to accept nursing care and how this was managed by the provision of information. In one critical incident, a participant described a situation in which a patient was reluctant to transfer to another hospital. In her view, this was caused by communication difficulties. A paramedic ambulance driver and a junior nurse were trying to cajole a patient into hospital transport in order for her to be transferred to another hospital. The patient was unaware of the impending transfer. Communication problems that had led to the patient remaining unaware of the transfer plans may have been exacerbated by the communication patterns portrayed in the incident:

This old lady who must have been 85 who was shouting and creating, and this nurse...stood next to her with her arms folded and said to her "what are you going to do" so I sat on the bed , got the other girl to uncross her arms and sit on the bed and told the paramedic to go and get a coffee. This old lady hadn't been told that she was going to a rehab hospital, she must have been told, but she hadn't cottoned on at all that she was going. She had no intention of going... she played hell..., then the consultant came along and he went on bended knee and apologised - and he spent the next hour with her, with all of us, trying to convince her. She kept agreeing - getting off the chair, virtually, and then changing her mind... (Interview 6)

The participant had identified that inadequate communication between staff and the patient had contributed to the patient's reluctance. In her view, inadequate communication had led to the patient being unaware of the transfer and was further demonstrated during the resulting discussion. She described:

...and this ambulance man was saying " I've got to go, this is crazy..." it was really

getting to me. I started making towards her with a pair of slippers...I found myself doing that... trying to get those slippers, I didn't actually get them on... but I realised when I'd got to her "what am I doing" and the consultant said "just a minute" - I felt really bad.... overwhelming... waiting, that's when it happens... in the end she went, but it should never have happened like that... (Interview 6).

The patient eventually agreed to the transfer. The extent to which the patient freely agreed to the transfer can be questioned.

In another incident, communication difficulties were cited as a main cause of the reluctance of a patient to have a catheter inserted. The patient was in urinary retention and was initially adamant that he did not want the catheterisation to be carried out. The participant suggested that his refusal was based on misinformation about the time for which the catheter would be left in situ and the prospect that a female nurse would carry out the procedure. The nurse described:

I think he thought it was long term, that was the thing.. after a while, he reluctantly agreed... it was the male nurse who swayed it and ... he was uncomfortable..he initially thought that a female nurse was going to do it... (Interview 8)

The patient eventually agreed to have the catheterisation. The participant suggests that lack of information about the procedure may have contributed to his reluctance. Apart from the description given in the critical incident, there is not further evidence as to the quality of this agreement. The agreement might have been made under pressure. The participant recalls:

We left it a day ...for him to realise, that one more day without urinating... I think he thought it was long term, that was the thing after a while, he reluctantly agreed... he didn't fully agree.... I think he agreed with reservation...I didn't think it was fully viable, he was unhappy... he understood, everything was explained... he agreed by pressure, but I think he agreed because he was in tremendous pain... afterwards he said "you should have done it sooner" (Interview 8)

It is interesting to note that despite the concern of the participant to get the consent of the patient, in his view, there was no choice but to carry out the catheterisation. This incident provides the first indication expressed by participants of a sense of a strong determination that

nursing care will ultimately be administered.

(if the patient persisted in his refusal) he would have to be told it must be done..., it was hurting him so much, he couldn't pass urine, it was the only option. you don't want it to get that far. I think there are times - maybe.. when there is no option - but I think there's a fine line and you must have good reasons to go without consent if there had been a legal battle, I think the surgeons would have come up quite well, because of their reasons behind it. (Interview 8).

Given this strong determination to carry out care, the participant's understanding of the role of informed consent prior to such nursing care procedures can be questioned. The participant was concerned not to proceed without the patient's agreement, but was prepared to do so if necessary. Seeking consent, or rather informing the patient about the procedure can be regarded as no more than a courteous gesture.

In another incident, a participant described how a lack of trust in the staff, not merely communication difficulties had led to a patient's refusal to comply with care. In this incident, the problem was not easily resolved. The incident involves a patient, a veterinary surgeon who refused intravenous medication because of his concerns over the way they were administered.

He was worried that people don't watch their watches when they give the (antibiotic) they don't give it properly, over 5 minutes, and he feared that they were giving it too quickly...he said that if his temperature were to go up, he would discuss it again..

H.A. How did you manage his comments that it was not being given slowly enough?

I accepted his observation and said that if we carried on with the (antibiotic), perhaps he could tell us what our job was.. and perhaps nurses would go over the top in timing it and give it as an infusion and not a bolus and appreciate how sensitive this was for him...there may be ways around it but he still wasn't happy...The first lady I mentioned had a pacemaker infection and went on to have a coronary. I didn't tell him that exactly, but we'd had the same problem with not getting on top of the infection, for different reasons..I didn't feel it was right to frighten him, although it may have made him realise what might have happened. (Interview 26)

In this incident, discussion focused on whether the participant felt that the patient's decision amounted to an 'informed' refusal. Despite the extensive knowledge of the patient, the participant was uncertain whether this 'very informed' patient was indeed 'informed enough' (or substantially autonomous) to be aware of the implications of his refusal. In this case, the participant set a very high standard for what she would consider an informed refusal. She was not working with a concept of substantial autonomy with which to assess the validity of a patient's consent.

While communication and information giving difficulties were identified as playing a role in contributing to the reluctance of a patient to undergo a nursing procedure, communication and information giving strategies were also employed to remedy a situation in which the patient was reluctant to have a procedure undertaken. An incident in which a patient was reluctant to have a naso-gastric tube was described:

I went and sat with her and told her what I wanted to do, that it wouldn't be forever, I left her to think about it, I went back, she had a few questions, she was happy for me to do it, it was the end of my shift, but I stayed on and we did it in her own time and it worked really well. (Interview 11)

It was discussed why this approach was perceived not only as good practice, but was also successful:

I think it was because we did it in her own time.. everything went slowly, I already had a relationship with her and I think that made a difference, she knew exactly what was happening. (Interview 11)

The patient was not hurried into having the procedure. That is not to say that she consented to it. We discussed whether the participant had been reluctant to accept the care.

Yes. just the initial thought, and obviously when I explained that it would be uncomfortable, but as far as I was aware from talking to other patients, you do get used to it. I was able to dissipate most of her anxiety. (Interview 11)

Another participant described a patient who requested more information

A patient who had a new tablet, I took it to him but I hadn't told him what the side effects were. He wanted to know and didn't take it until the doctor spoke to him...he was young, 50, I couldn't give him all the info...

H.A. Does he strike you as an unusual patient?

Yes (laugh) most of them don't question. He said that no one tells you side effects and you have to ask. I suppose it's right....I don't know if he'd had a bad experience or someone in his family had...most people you don't have to give them much information... (Interview 7)

In another incident, a patient who was reluctant to take the prescribed insulin, agreed to take the prescribed dose, following a thorough explanation of the rationale -

A diabetic, whose sugar levels were all over the place. He felt the doctors were prescribing too much insulin, he was getting hypos (hypoglycaemic attacks) He was feeling quite low... I explained that he needed the insulin in the morning but that we would reduce what he received in the evening..he felt that the insulin was too high both in the morning and the evening... but when I explained, he agreed. I told him I would check it again during the afternoon. He was happy with that in the end. I had to show him his chart....I think he was still a bit apprehensive..., but I think I had reassured him that I would check his sugar level... (Interview 28)

The patient was waiting for a kidney transplant, which was an added reason for achieving good control of his blood sugar levels. We discussed whether the patient was fully aware of the implications of his reluctance to have insulin.

I think he realised that insulin gave him hypoglycaemic attacks but I don't think he understood how important it was to keep his insulin levels under control, for a kidney transplant in the future. (Interview 28)

Confidence in nursing staff in addition to skilled communication may be seen as an essential pre-requisite to good nursing practice. The use of information to relieve patient anxiety has been thoroughly explored and is well documented. Early nursing research identified that information giving prior to a proposed procedure can result in reduced patient anxiety,

(Hayward 1975). There is evidence in the data from this study that patient reluctance to undergo nursing care procedures is sometimes due to a lack of information about the intended procedure. When the information deficit is addressed, the patients accept the proposed intervention. It might be expected that patient anxiety is a cause of reluctance to undergo a nursing care procedure. If the anxiety is removed, so might be the reluctance. If this argument is accepted, then information giving is seen as a pragmatic response to a clinical situation. Information giving relieves anxiety and thereby reduces patient reluctance to accept nursing care. In Chapter 4, it was suggested that nurses gave information when compliance with nursing care was not expected. In this chapter, there is evidence that information is used in a similar way. Information is used to inform and reassure patients about forthcoming procedures and thereby achieve their compliance.

Restoring an information deficit might be sufficient to remove the reluctance of some patients to undergo nursing care. Clearly information giving is a component of seeking informed consent. However, it must be acknowledged that information giving in this way may not be sufficient for meeting the demands of informed consent. Information given to relieve anxiety might not be the same as that given to promote patient choice. For example, in one study, Whalen (1984) found evidence of a tendency to minimise the undesirable consequences of a proposed procedure and to maximise the good.

There is evidence that participants use information giving as a means of removing patient reluctance to accept nursing care. It is emphasised that this may not amount to seeking consent. There is also initial evidence of a sense of determination; that nursing care will be carried out but that participants prefer to manage the reluctance of the patient before they undertake the procedure. This will be explored in more depth in a later section.

5.3 Use of negotiation and compromise to reach an agreement.

There is evidence that participants supplement or replace information giving with the use of negotiation and compromise in order to reach agreement about the proposed nursing intervention. However one participant cited a negative example of this and expressed her view that sometimes nurses make a compromise as a way of facilitating co-operation. They then fail to keep their side of the bargain:

(they say) let's get you out of bed now, they don't want to, then the big guns might go in and say come on now, out of bed, at least sit out while I make your bed..." or

"let's wait until the physio (physiotherapist) comes" and those bargains are rarely kept, I've noticed...(Interview 19)

Another participant recounted an incident in which negotiation was used, in her view, to good effect. A patient did not want to be turned in bed, in order to prevent the development of pressure sores. The nurse and the patient were able to negotiate a compromise, and this, in the nurses' view, had given the patient some control over the situation and she agreed to be turned:

A patient who didn't want to be turned and wasn't turned at home. I explained that we had different mattresses. I said fair enough, but would she agree to have a buzzer and call us when she wants us, but that if it gets to 4-5 hours, then I must draw a line at that and would she agree to that? I gave her a condition: if you make a deal, a compromise, you are giving them a bit of leeway. she was happy with that.

H.A. Did she buzz before the 5 hours?

She did, but we had given her the control. She didn't want us to take over.
(Interview 25)

Here is another example in which the nurse was not prepared to allow the patient to refuse completely. Again there is a sense of determination that care must be carried out. There was a limit of five hours at which the patient could no longer refuse nursing care - at which the nurse must "draw the line at that". The nurse's reaction is indicative of a belief that while patient preference may influence that care, it should not dictate it. However, the nurse demonstrated a conflicting belief. She was aware that she couldn't give care without the patient's consent:

I had done my bit..I weighed up how much trouble I could get into for not turning and for turning... that could be assault. This is what she would have done at home. That was my argument. (Interview 25)

The nurse was aware that, although she felt she ought to give the required care, she could not enforce care on to the patient without her consent. In this situation, she was able to reach a compromise. In a later incident, the same patient was reluctant to use a pressure relieving mattress. We discussed whether the nurse would insist that a patient must stay on a particular mattress. In the course of our discussion, the participant oscillated in her view as to whether the

final decision about nursing care should lie with the patient alone.

I think it would be a team decision, we'd discuss it as a team...and the family as well... if they can help and encourage their relative, but at the end of the day we must bear in mind what the patient wants...it has to work as a partnership. OK we've trained and got experience, but the patient has looked after themselves...they have to decide some things for themselves. I think you have to negotiate. You have to work up a relationship where you can say why they need something... at the end of the day it's their decision, as long as they are in their right mind... and they have been given all the information...there's nothing more you can do. (Interview 25)

When a patient is reluctant to accept nursing care, there is evidence that information is given and negotiation is used to achieve the patient's expressed agreement. Clearly it is appropriate to discuss with the patient the reasons for the refusal and to give further information if required in order to facilitate his or her consent. There is an acknowledgement that care cannot be given without the patient's agreement. However there is also evidence that participants are intent on carrying out care. A tension emerges between the need to administer care and the need to do so with the patient's consent. This tension will be examined in subsequent sections.

5.4 Initial information giving and negotiation do not always result in the patient's agreement of the procedure

In the previous section, information giving and negotiation were used to facilitate the patient's expressed acceptance of the proposed nursing care. In this section, incidents in which the patient's agreement is not achieved by initial information giving are discussed. In one incident, the patient was reluctant to have a catheter. The participant described an incident:

I was on night shifts and the patient had a urinary infection and was incontinent, she didn't know she was doing it, it was night, we had enough going on never mind her wetting the bed. So we had to consider catheterising her ...(note how factors other than the welfare of the patient, play a role in the initial nursing decision that the patient should be catheterised.)... she wasn't having it basically, she didn't want the catheter putting in at all... she said "I want my daughter in here.." It was the patient's wishes and we left it on that first night, put the patient first and made sure she had what she wanted, the daughter came in the next day and she still wasn't particularly happy, but on the second night, we spent some time explaining that it wouldn't hurt and that we

would be careful and she agreed to have it, so actually it took two nights and days...with two different shifts.. to get her to have one... (Interview 13)

The participant was adamant that a catheterisation would not be carried out until the patient had reached this point of acceptance.

I think it is up to the patient, they shouldn't be pushed. She wasn't happy.. you can't make someone have something... (Interview 13)

The dichotomy already identified re-emerges. The participant did not want to undertake the procedure without the patient's expressed agreement. However, in the participant's view, there was no alternative but to undertake the procedure. The participant suggests that the procedure would have been undertaken, even if the patient had not ultimately accepted it.

Eventually, yes, something could have been done, we could have got a medical team involved..but at that stage, she was going to come round eventually...(if she had persisted in her refusal) I think the relations and medical team would have become involved...I think she would have had it, she wouldn't have been that difficult, but obviously more senior people would have become involved... (Interview 13)

It is interesting to note that the participant describes the patient's non-compliance as 'difficult'. The involvement of senior staff may be entirely appropriate, given the potential seriousness of a patient refusing an intervention and the difficulty of assessing whether that refusal is valid. Or it might be perceived as greater pressure to be applied until the patient eventually concedes to the procedure. Significantly, though, not giving nursing care was not perceived to be a viable option.

In another incident, a patient was reluctant to have a catheter. Again, workload, in addition to clinical need were cited as reasons for putting in the catheter:

We have a patient with a left sided stroke, middle aged, fiercely independently, always lived alone, very clean and tidy, concerned about her appearance, however she was being incontinent, hourly almost, so from a clinical point of view we were thinking she was quite heavy to turn, she had this pressure sore that could be damaging...also it's not nice to be in urine, also the extra workload upon us, so the option of catheterisation

was brought up. (Interview 4)

The nurse described how initially, he had approached the patient and suggested the catheter. When she seemed unhappy about this, the nurse asked an auxiliary to talk to the lady. He felt that the patient did not have sufficient information to understand what the procedure involved:

She sort of agreed, but not to the extent that...we were unsure whether she had fully got the gist of what a catheter was. So I didn't feel that I was happy to let someone go and catheterise her, because I felt she didn't understand it fully, so we left it. Fortunately one of her relatives came in, who had had a catheter in the past and she talked her into it, after that was done., she agreed to be catheterised. I felt that that was handled pretty well. (Interview 4)

Again, despite the nurse's concern not to proceed with catheterisation without the agreement of the patient, not giving the catheter was not considered to be an option. The nurse predicted that catheterisation would have happened eventually, but it was preferable to do so with the patient's agreement:

She'd have been catheterised eventually I'm sure, but I don't know when or to what extent it would have got to before she was catheterised so I felt we got her consent before we proceeded and were very aware of making sure that she understood what the catheter was. (Interview 4)

The participant described what he felt to be a satisfactory outcome to the situation - the patient expressed acceptance of the procedure. The extent to which this was a voluntary acceptance can be questioned.

It was good that when she was eventually catheterised, she was aware of what was happening, she understood why we were doing it, we'd explained what it was for, why she needed it, why we thought she ought to have it and why she'd probably be happier if she did have it, for her own self respect. She kept mentioning that she didn't like giving us all this extra work: she'd say "I can lay here for a bit longer" so that she'd probably feel better with the catheter. I felt that it was good that she actually knew what was happening and that we didn't turn up with a tray and say "this is what we are going to do" which does happen at times. (Interview 4)

These incidents demonstrate that when a patient does not initially accept nursing care, information giving is 'stepped up'. Participants indicate that they are not happy to withhold care, but are also unhappy to give care in the absence of the patient's agreement. They endeavour to achieve the patient's agreement and go to great lengths to achieve this. Information is given until the patient concedes to the administration of the procedure. It is argued in Chapter 1 that information giving is essential to facilitate the patient's substantially autonomous authorisation. When a patient is reluctant to accept a care procedure, it is appropriate to discuss the procedure with the patient. However it is important that the information giver recognises that the patient's agreement should be voluntary. The patient should not feel pressurised into complying, This would affect the voluntary nature of his agreement. Furthermore, a tension emerges. Many participants in this study recognised the need to obtain the patient's consent but were non-the-less intent on carrying out the care. Clearly the patient's refusal of consent is a potential block to the administration of care. There is an initial indication that should the tension between not be resolved, care would none the less be administered.

5.5 Further information giving. The point of 'expressed acceptance'

Participants involved in this study were reluctant to carry out nursing care if the patient was not happy to receive it. If initial attempts to reverse the patient's reluctance were unsuccessful, further information was given to the patient in order to achieve the patient's expressed agreement to the procedure. There is evidence in the following focus group discussion that information was not necessarily used to facilitate the patient's meaningful decision making.

Participants in the focus group discussed:

H.A. Are refusals always upheld?

No not at all. We badger and badger.

You get cross - you want me to treat you? (Focus group 1)

Another group of participants described:

We abuse the power we have. We persuade patients a bit too much. We use power - well not force them but to get them to do what we want . . .

Coax them.

If they don't want a wash we'll say 'You really do need a wash 'cos you haven't had one for so many days - if you don't have one now it will have to be a lot later.' This really is the best time for us . . . they end up feeling obliged to have a wash . . . a little example. (Focus group 4)

The group discussion continued:

For someone to actually refuse they've really got to be quite determined. . . when you say . . . you go through all the stages - you go, your colleague goes and then a psychiatrist comes in by the time you've gone through that - and they are still determined.

...They can only refuse if they are strong enough.

They have to be very strong considering the pressure that's put on them.

(Focus group 4)

While it is clearly appropriate to investigate the reasons why a patient is refusing a nursing care procedure, (Wear 1991), participants in the focus group discussion indicate that the line between what is acceptable and unacceptable pressure may be crossed.

These general assertions concerning how information giving is used to facilitate a patient's expressed agreement to a nursing care procedure were reinforced by data collected through critical incidents. In one critical incident described, a patient was reluctant to have a naso-gastric tube inserted:

We have a patient on the ward who is refusing food and drink, we have discussed with her many times the possibility of passing an naso-gastric tube and offering some nutritional benefit... we're currently a week down the line of just talking about it and giving her the rationale which we believe she is taking on board. Today she is

changing her mind... so we are going to attempt to put the tube down we are going to talk to her again when the tube arrives in case there are any misconceptions about what we are talking about in case there's something we've missed. (Interview 6)

It is argued later in this chapter that when a patient is reluctant to undergo a procedure that is clinically indicated, practitioners have a duty to persuade the patient into accepting the recommended course of action. Persuasion involves the provision of further information and the evaluation of that information by the patient. This provision of information is necessary to facilitate the patient's decision making. It helps to ensure that the patient is 'substantially' informed about the nature of his or her refusal and the potential consequences. The patient's refusal might be a reflection of his or her immediate, that is unevaluated, reaction to the proposed procedure. The refusal might not be a considered or evaluated response. The provision of information and the evaluation of information with a practitioner can help the patient to make a substantially autonomous choice. Reference can be made here to the concept of first and second order desires as defined by Dworkin (1988) (p108). Participants in this study are acting reasonably when they react to a patient's reluctance to accept a care procedure by giving further information. Provision of information might assist the patient in the evaluation of his or her reaction towards the intended procedure. However, it is the way in which this information is given and the attitude of the information provider which is important in facilitating patient choice. This point is discussed further in this chapter.

In another critical incident, a patient was in need of an enema. Again, the strategy of continual information giving was employed until the patient accepted the enema. The tension between concern to carry out the procedure and not wanting to do so until the patient had accepted it is evident in the participant's description of the incident.

An elderly lady, very pleasant and very cheerful, one of her problems was that she was very constipated, very impacted, when we went over with the enema, and explained it, she didn't want it. She had to have it because she was so impacted, in the end we managed to persuade her although she was quite set against it at first, we had to talk her through it...it didn't take very long...about 10 minutes, a good 10 mins. In the end she said "well if you've got to do it, you've got to do it" (Interview 10)

Despite the participant's view that the enema was essential, the participant was also adamant that she did not insist that the intervention be carried out:

I mean, I wasn't saying "come on you must have it"...I think any longer, if she had been adamant, it would have been unfair to have grilled her for any longer than that...I'd have pulled away and tried again later, having got advice, or got another colleague to go over...or give me advice ...a different way to go about doing it. If I'd sat with her for 10 minutes and she wouldn't have it, in view of that she wasn't confused, I wouldn't have given it, I'd have had a rethink, perhaps tried again later or the next day... in the end she did consent, but it was with reluctance. (Interview 10)

There is evidence that when the patient persists in his reluctance to undergo a nursing care procedure, additional information is given until the patient eventually concedes to whatever is proposed. This technique seems to be 'effective' - that is, the patient eventually expresses agreement to the proposed intervention. However the voluntary nature of the agreement can be questioned.

One participant described:

if she still said NO! , I don't know what we would have done because most people would have agreed by then, it would have been unfair to carry on longer... (Interview 10)

The evidence presented in the critical incidents suggests that the described approach, of continual information giving, does usually result in the patient's eventual acceptance of the procedure. It is a more subtle approach than saying to the patient "*come on you must have it*" (Interview 10). From the data, the voluntariness of the agreement cannot be determined. It is not clear whether the information giving resulted in the patient's genuine acceptance of the procedure or whether it merely made the patient "*feel obliged*" (Focus group 4) to comply.

5.6 The role of persuasion

There is evidence that continued information giving plays a major role in the process of gaining consent prior to a nursing care procedure. Some participants referred to this process as persuasion.

The role of persuasion in situations of informed consent has been widely commented on. Faden and Beauchamp (1986) define persuasion as:

the intentional and successful attempt to induce a person , through appeals to reason, to freely accept - as his or her own, the beliefs, attitudes values, intentions or actions advocated by the persuader (p347)

Persuasion entails that the patient 'freely accepts' the 'beliefs, attitudes, intentions or actions' of the persuader. Drawing again on the work of Dworkin (1988), persuasion, correctly employed might be a necessary way of assisting the patient to evaluate his or her feelings about the proposed procedure. Reluctance to undergo a procedure, which reflects an unevaluated desire, might through the process of persuasion be re-evaluated and the patient come to accept the procedure. The patient is presented with convincing reasons why he or she should adopt a particular course of action. It has been argued in Chapter 1 that patients require assistance identifying their best options for care and treatment. Persuasion facilitates the patient's evaluation of what he or she really wants. In view of this, use of persuasion is compatible with the ethos of informed consent. True persuasion does not affect the voluntary nature of the patient's decision.

Many commentators argue that the health care provider has a duty not only to give information about care possibilities but also to persuade the recipient of care to accept the course of action considered most appropriate. They argue that the health care provider is usually in a better position to evaluate the different care options than the patient himself. Indeed, many proponents of informed consent argue that consent is a process of assisted decision making (see Chapter 1) Persuasion may be a component of this. Faden and Beauchamp (1986) argue:

persuasion is a ubiquitous form of interpersonal influence that figures prominently in the consent decisions of most if not all patients...we have already stated our position (in a previous chapter) that persuasion, properly understood, poses no problem for informed consent...Indeed it is the model form of influence in informed consent contexts: it can enable and even facilitate substantially autonomous authorisations" (p345)

In Faden and Beauchamp's view, not only is it permissible for a clinician to employ the use of persuasion, but it may also be a moral requirement for him or her to do so.

frequently in clinical situations, professionals would be morally blameworthy if they

did not attempt to persuade their patients to consent to interventions that are medically necessitated. Reasoned argument in defence of an option is itself information and as such is no less important in ensuring understanding than provision of facts (p347)

These same sentiments are echoed by Culver and Gurt (1984) who argue that although a valid consent cannot include coercion, strong recommendations, even those which are forcefully given, are not coercive.

we think that sometimes it is morally praiseworthy for a physician to put pressure on a patient during the consent process (p174)

It is argued that persuasion is compatible with meaningful decision making. Persuasion is an appropriate response to a patient who is reluctant to undergo a nursing care procedure. However it is important that nurses have a clear understanding of the nature of persuasion when they seek to challenge a patient's understandable reluctance to undergo a care procedure. Persuasion cannot be used to describe an interaction in which information is relentlessly given so that eventually, the patient is 'bulldozed' into compliance. True persuasion, as defined above, cannot be achieved if the persuader has a prevailing mindset that that the procedure will be ultimately carried out. Crucial in the use of persuasion is an acknowledgement on the part of the persuader that the patient has a choice and can reserve his right not to accept the care proposals. Persuasion entails the facilitation of the individual's free choice. The data in this thesis does not illustrate the exact nature of the eventual agreement between the nurse and patient. However it is the attitude of the information giver that is important in the facilitation of the patient's free choice. There is evidence in this study that many participants did not acknowledge the patient's right to refuse. It is reasonable to assume therefore that they did not appreciate the importance of the patient's free choice. They portrayed a determination that care would be ultimately delivered irrespective of patient choice. Given this approach, it seems likely that participants were not engaged in persuasion, but a different form of influence.

5.7 Information to facilitate choice or compliance?

The data for this thesis provides evidence that information giving attempts are stepped up when they do not initially achieve the patient's expressed agreement to the procedure. The prevailing philosophy among participants that care must be delivered, preferably with this expressed agreement is indicative that this information giving does not amount merely to persuasion, but to a more forceful form of pressure to comply.

Various studies have identified that information giving – even when this amounts to a full disclosure – might constrain rather than facilitate patient choice. The evidence of McCormack (1998) and Levy (1999b) have been cited in Chapter 4. In an early non-nursing study, Strong (1979) identified that parents had little real choice about the care and management of their child, despite being ‘involved’ in the decision making. Communication between professional and the parent was described as an ‘orchestrated encounter’ in which there was a sense of determination that care would be carried out, preferably with the parents ‘on side’. The way in which non-nursing health care professionals control the outcome of conversations with patients has been widely discussed, (Drew & Heritage 1992) and (Fairclough 1989).

Looking specifically at nursing, a similar finding was concluded by McCormack (1998) in his study of elderly patients’ involvement in discharge planning. He described that although information was routinely given to patients, this did not facilitate their ability to make a choice. He commented:

When detailed information was provided, this often appeared to be ‘coercive’ ie it was provided in a way that encouraged patients to follow a particular decision (p185)

The data in the present study indicates that when a patient is reluctant to agree to a nursing care procedure, communication styles emerge that do not facilitate the patient’s consent to the procedure but which exert pressure on the patient to accept the planned course of action. The voluntariness of this acceptance can be questioned. Participants in this study described unacceptable pressure exerted on patients to ensure their compliance with care procedures. There is a fine line between persuasion, properly employed and unacceptable pressure on a patient to accept a procedure. It is argued that the difference between the two lies in the nurse’s attitude to the administration of care. The aim of persuasion is the patient’s free acceptance of a procedure. Persuasion entails choice. It is argued that persuasion facilitates the patient’s substantially autonomous authorisation of a procedure. This should be contrasted with situations in which undue pressure is exerted on a patient to accept a procedure, where the aim is the enactment of the procedure, irrespective of patient choice. If nurses approach information giving with the aim of facilitating patient choice, this may guide them towards persuasion rather than exerting undue pressure.

5.8 The fine line between an 'expressed agreement' and consent

Given the understandable reluctance of a patient to undergo an unpleasant nursing care procedure, there may be a fine line between the expressed agreement and actual consent of a patient. The extent to which an agreement is voluntary can be debated. This was articulated by one participant:

I think no one wants the tube . I think what they actually consent to is the logic behind it, that's what they are actually consenting to..They've never had a tube before, how can they consent to it?... we talk about informed consent, but it's not....really the consent comes when you actually start putting down that tube, slowly, listening, they might have agreed in principle, but they can still change their mind...you need consent when you are doing procedures- often I've seen people say " Oh she's agreed- get in there quick"...its the worst possible scenario, just because they've agreed. All procedures should be done slowly because all patients, you should still seek ongoing consent. (Interview 5)

One participant described how knowledge of the patient might help to identify this distinction. The participant described:

The doctor had said that the patient needed a naso-gastric tube and told the patient, who was very upset, so I went back to him later and talked to him some more, why he needed to have it done. It was persuading him to have it done, saying "go on you have to have it done". We waited for his fiancée to come in and she persuaded him to have it done, he was really under a lot of pressure...he did have to have it done, I found it unpleasant..

H.A. Was he refusing or more...?

No, he was reluctant... but I knew (the patient) and I knew that he was depressed and fed up. No matter what we said it wouldn't have made any difference, I like to think that I know the step where depression and needing to be persuaded steps over into refusal... from body language.. I would like to think that if he said to me 'I don't want it done', I wouldn't have shoved it down his nose, but he was reluctant...I explained to him the benefits of having it done.. I knew he didn't want to have it done, but I think there is a difference between not wanting something done and refusing consent...in the

same way that patients don't have a choice about coming into hospital.. you don't want the surgery but you are not going to refuse. (Interview 19)

The nurse described his relationship with the patient as essential in determining the weight of this refusal:

That's where your relationship with the patient comes in, and your experience. I would be pleased if a junior nurse came to me and said 'this patient has refused' because they might be picking up on the fact that they are reluctant, a more experienced practitioner may be able to see the difference between reluctance and consent. (Interview 19)

A frequent observation arising from the discussion of critical incidents was that the discretion of the nurse plays a large part in any nursing care activity which involves a reluctant patient. One nurse, for example, might be more determined than another in achieving the patient's expressed agreement. She described:

I think some nurses might have gone over and said "come on let's do this." I've seen it happen. I don't think it's right...a patient may say "I don't like that nurse...". some nurses are more brisk in their manner. They are very good nurses and they know their work but sometimes the attitudes they give out are more.. (Interview 10)

The idea that every nurse is different and may therefore manage a given situation in different ways was widely held. It was also accepted that this situation was inevitable and could not be controlled:

Yes. it's your personality, what you think...it's not an easy subject..there's so many view points...I think it's up to the personality.. if you get anyone (member of staff) who says "I know best" there's nothing you can do. That's their viewpoint. You may try and educate them...you can see it in people.... (Interview 22)

It must be accepted that much of nursing practice is carried out 'behind closed curtains' and is largely self regulated. Responsibility for the quality of individual nursing practices lies with the individual nurse. Every nurse is indeed 'accountable for his or her actions' (UKCC 1992). This applies equally to the practice of obtaining consent prior to nursing care procedures as to other nursing activities. The practice of obtaining consent prior to nursing care procedures however -

unlike other nursing care activities and unlike consent gained prior to medical research or surgical procedures - has not been subject to wide public debate and scrutiny. While the U.K.C.C. requires that consent should be sought prior to 'any treatment or care', (U.K.C.C. 1996) (p17), there are no set procedures which should be followed in order to facilitate patient consent.

How nurses gain consent from patients prior to nursing care interventions may be largely down to the discretion of the individual nurse. The participants in this study described this with an accepting resignation. Practice cannot be regulated and whether too much pressure is used (for example) does rely on the integrity of the practitioner. However, this does not mean that nursing practice in this area cannot be scrutinised for good practice recommendations. Individual nursing practice should not depend on the individual view point of each practitioner, without reference to external guidance and regulation. Standards of practice can be set and maintained. Perhaps the important thing to focus on is the professional integrity of the practitioner. It is essential that the nurse understands the ethical and legal principles that underpin his/her work and has a working ethical framework, which is consistent with legal principles, to guide his/her practice. Information giving is the appropriate response to a patient who is reluctant to undergo a care procedure. However it is the attitude with which the information is given that is important. That is, that information giving should be used to facilitate rather than constrain patient choice. When patients are reluctant to undergo care procedures they need information to facilitate their decision making. However information giving should not be used to exert pressure until the patient feels obliged to comply and thereby express his or her agreement. If undue pressure is exerted on a patient, his or her agreement may not be voluntary and may not therefore represent his or her informed consent. The different approaches to information giving and the influence of this on patient choice are examined in the following section.

Interim summary

Nurses experience a dilemma in practice when a patient is reluctant to undergo a care procedure. Most nurses are aware that they cannot proceed without the consent of the patient but do not see withholding care as a viable option. To resolve this, patient reluctance to undergo a proposed nursing care procedure is usually met with the continued provision of information in an attempt to facilitate an agreement. It is argued that information giving is appropriate to ensure that the patient has made a substantially autonomous choice to refuse care. However there is evidence that nurses do not use information giving in this way. When

standard information giving procedures fail to achieve an agreement, the pressure of information giving steps up. Various attempts are made, by various means, to encourage the patient to accept the care procedure. Participants in this study described the great lengths undertaken to achieve this with high rates of success. There is a tension between the requirement for consent prior to an intervention and the requirement to undertake the intervention. Usually, the patient expresses an agreement to undergo the procedure. It is not clear from the data presented in this thesis whether the expressed agreement of a patient constitutes a genuine consent or an act of compliance. The differences between informed consent and compliance are discussed in Chapter 4.

Some participants describe this information giving process as persuasion. However, persuasion entails the free acceptance of an individual to the proposed procedure. Free acceptance implies that the patient is equally free to refuse the care. In this study, there is evidence that patients are not given the opportunity to refuse care. There is evidence that some participants may be willing to proceed with nursing care even if the patient does not eventually consent to the procedure. Examination of the documented communication styles of health care professionals presented in the previous section indicates that decisions about health care are decided before consultation with the patient. The data presented in this thesis is also indicative of this concept. Given the lack of recognition of participants of the patient's right to refuse care and the seemingly unalterable nature of the nurses' decision to proceed with care, it is suggested that persuasion is not an appropriate description of the communication styles described.

There may be two ways in which nurses fail to get consent when the patient is reluctant to undergo a proposed nursing care intervention. Firstly, nurses may put mounting pressure on the patient so that he eventually agrees to the procedure, but this agreement represents compliance rather than consent. Secondly, throughout discussions, nurses indicate that they may be prepared to proceed with the intervention in the event of the patient's continued reluctance; that is, without consent. There is a strong indication that although nurses state a preference for obtaining the patient's agreement, they would proceed without it if necessary. In the incidents described so far, the agreement is reached so it is not clear whether the nursing care procedure *would* be undertaken without the patient's agreement. Clearer indication about this is given in the following sections.

There is an indication that although participants prefer to get the consent or even merely the expressed agreement of a patient prior to a care procedure, they would be prepared to proceed

without it. The patient's consent is preferable but not essential prior to nursing care procedures.

5.9 The patient who does not express his agreement to nursing care procedures. Care is administered because it is considered essential.

Participants in this study described how the process of continual information giving usually achieves the patient's eventual expressed agreement to the proposed procedure. In this section, the management of patients who continue to refuse a care procedures is discussed.

In the focus group discussion, there is an oscillation of views concerning the management of patients who do not express their agreement to nursing care procedures. At some points in the discussion, participants described how they felt the administration of care to be all but inevitable, irrespective of patient wishes, while at others they expressed the view that the patient has a right to refuse. Excerpts of the discussions are presented below.

We will do things if we believe we have a medical reason to do it.

If you know that someone is getting "bunded up" and is in a lot of pain and you have nursing knowledge ...everybody agrees that that's the problem, - you do something that you know will make them feel better - even if you know they are not happy about you doing it

(Focus group 1)

Later on, the discussion focused on the idea that nurses were prepared to administer care, irrespective of patient choice.

You believe that you are justified in what you're doing. All I can do is be sympathetic & gentle ... you give them a bit of control, but basically you're going to do it.

We need to do so many things...

People come into treatment. It's part of the deal

(Focus group 1)

Another group of participants echoed this view.

I don't see why we shouldn't give care if we know that will benefit the patient

I think we just have to give ourselves credibility because we do know just as someone who's a representative in a court of law ... they are going to know. I'm not saying that's right...

(Focus group 2)

Many participants felt that a patient's reluctance or refusal may be overridden. One participant gave the following example:

She didn't want you to do it (chemotherapy) because she felt sick but she liked having her feet rubbed - so we did that... You'll never make it better because she didn't want you to do it

You think what you do is justified and you have to do it. All you can do is negotiate the time and try and give the patient a bit of control

You take professional decisions. I do know best and I will do this.

(Focus group 4)

Many participants did not consider a patient's refusal to be binding. They felt that if a nursing care procedure was clinically indicated it should be carried out, irrespective of the agreement of the patient.

However, at other times in the group discussions, participants expressed the view that the patient has the right to refuse nursing care procedures and that there has been an increasing recognition of this right over recent years. One group of participants discussed:

Patients can refuse - that's changed over the last few years.

You try and explain why, but if they still say no, you don't do it.

Patient's rights, patient's charter - named nurse.

(Focus group 5)

Another group of participants discussed:

You give them info if they still say no - then say fine.

I think things have changed a lot in that respect. A few years ago if people refused, you wouldn't take any notice of them.

Now we do respect their opinion.

(Focus group 4)

The dichotomy of the perceived necessity of carrying out the procedure together with an awareness that it is not permissible to do so without the agreement of the patient was identified in the participant's discussion. One participant recognised the legal principles that guide practice.

I think the charge of assault is becoming more and more common quite frankly and you don't have to do a lot to get charged with an assault...

So you kind of use different approaches and persuasion which is all part of the nurse's artillery of skills, I imagine. (Focus group 5)

The focus group discussions illustrate an oscillation of views concerning the rights of a patient to refuse nursing care. Contrasting accounts of practice are portrayed. These constructed accounts are influenced by the discussion generated by the group. They are not direct reports of practice. Data provided by the critical incidents presents a more united picture.

The critical incident data provides evidence that nursing care will be administered in the absence of an expressed agreement by the patient. For example, in one incident, a patient was given subcutaneous fluids despite her refusal. The patient had had a stroke and had difficulty communicating. Unable to eat and drink, she required additional fluids; rehydration was considered essential. Intravenous fluids had been initiated twice. Although the patient could not speak, she could demonstrate her opposition to the administration of the fluids. Clearly, the ability of the patient to consent is questionable, but it was assumed by the participant that she

had this ability. On both occasions, the patient had protested and had pulled out the cannula. The staff were resolved that fluids had to be given:

She just shook her head because she just didn't want even the subcutaneous fluids going through, but it was really important, she wasn't taking anything orally, she was getting dehydrated, but she didn't want the subcut needle going in... she had to have it...there was no other way. (Interview 10)

The participant clearly did not regard respecting the refusal of the patient by withholding fluids as a viable option. The solution to the problem was found by another nursing member of staff. The solution combined an unconventional approach with benevolence.

The nurse got round it by getting some (anaesthetic) cream and put it into her back so it would be harder for her to pull out and she wouldn't have to see she had a needle anyway...they used the cream so it didn't hurt. She had the subcutaneous fluids. At first she didn't want it, she's much better now. I thought it was very compassionate of the nurse, she had obviously thought it through, rather than just going ahead. I thought it was a nice individual touch to get the cream... (Interview 10)

In the participant's view, the cannulation was carried out without the consent of the patient. However, the participant felt that the patient's resistance to the fluids lessened once the procedure had been undertaken. Whether or not it should be considered that the patient eventually agreed to the procedure depends on the reader's interpretation of the situation:

She was still frightened of the needle, but she was consenting by then, she agreed although she was still afraid.... she did leave the line in whereas with the ventflons, she pulled them out (Interview 10)

This incident illustrates that although the refusal was not respected, the nurse went out of her way to minimise the effects of the unwanted intervention for the patient.

Another incident indicates the (understandable) reluctance of nurses to respect the refusal of a patient to a perceived essential nursing intervention. The incident concerned a patient who persistently pulled out her naso-gastric tube. Again, the participant described the urgency of the care required. Respect for the refusal of the patient was not considered an option. Again, the

solution described below was to minimise the impact of the intervention by carrying it out as quickly as possible:

We have problems with naso-gastric tubes. We do have struggles with people, they pull it out and we put it back in . You do think this is wrong but without it they'd have no nutrition..a girl, she'd pulled out her tube, she was hardly eating or drinking...I tend to leave it for a few hours and try to explain... then do it quickly...I have put tubes down, given a bolus and taken it out again. (Interview 25)

The nurses in this incident did not respect the refusal of the patient. They proceeded with nursing care because they felt it to be essential. Their reasons for doing and their approach to care can be regarded as beneficent. The participants who described the incidents were concerned to cause minimum distress to the patient while implementing the care procedure.

Despite the demands of informed consent theory, it is nonetheless understandable that nurses might be reluctant to respect the refusal of a patient who refuses an intervention that is potentially life saving. If there is any doubt that the patient is sufficiently autonomous to make this refusal, it would be understandable to err on the side of caution and reach the decision that autonomy was not sufficient. However, there is no evidence that the refusal of the patient was overridden out of doubt about the ability of the patient to make a valid decision. The refusal was overridden due to the perceived beneficial outcomes of doing so. Nurses expressed their reluctance to respect a patient's refusal by appealing to the essential nature of the care involved. They did not see that there was any choice but for the patient to have the intervention.

Other incidents were recounted in which the patient's refusal was overridden. In these incidents, the care was not perceived as essential but merely beneficial to the patient. In one incident, a patient was in great pain and unable to sit in a chair because of the backache this caused. She refused all pain killers, including those administered by intravenous infusion. The staff were unhappy about this refusal and administered pain killers despite the patient's refusal. They were uneasy about this but justified their actions by appealing to principles of beneficence:

The Drs decided to give her pain killing syrup...it might have been unethical..

H.A. What do you mean by unethical?

She had refused morphine, but then to give her a pain killing syrup, she didn't know what it was...she was more comfortable, it did relieve her pain... she had no adverse effects.. and with her limited knowledge and refusal to listen half the time, it probably was the best thing for her...I suppose its me being her advocate... (Interview 12)

It is interesting to consider the nurse's interpretation of the term advocate. The nurse seems to interpret the term advocacy to mean 'acting in the best interests' of the patient - which, in this incident was perceived to be the administration of pain killers. The role of an advocate as someone who protects the patient's autonomy - which may have been infringed by the administration of pain killing drugs without the consent of the patient - was not considered. Also interesting to note is that the participant did not relate the occurrence of any debate or discussion over the ethical dilemmas presented in the scenario; whether, for example it was permissible to prescribe analgesic syrup by deceit. Instead, the participant described debate that took place with the palliative care team as to which analgesia should be the most effective. The nurse's reasons for giving the pain killing syrup were explicit -

it was just ridiculous to see her struggling ... (Interview 12)

It is interesting to note that the nurse viewed the refusal of pain killing syrup as 'ridiculous'. It seems that the patient's values were not taken into account by the nurse.

In another incident, the participant did not attempt to understand the values of a patient who persistently refused an intervention. She could not understand how a patient could reasonably refuse a catheter:

If she was not confused and had taken on board the explanation and still refused, having got all the information and taken it on board, I'd have thought she was a bit stupid ... (laugh) ... I can't imagine someone saying they don't want it. (Interview 15)

In a further incident, a patient refused to be catheterised. She was described as slightly confused but able to understand the reasons for the catheter. She was however, unaware that she was incontinent of urine.

I decided she needed to be catheterised. I discussed this with another nurse and explained the whole procedure to the patient - in enough detail for her to be able to understand what we were doing and that it would be more comfortable. She asked me "will it hurt" and I said "it might be ...". ...I think she thought it was a procedure that would be done and finished and she didn't realise it would be staying in. Before we started, she was saying "I don't want this, leave me alone" - but she was already lying in a wet bed. We had to wash her... (after the catheter had been inserted) ...Then she said "take it out, I don't want it in, I'm going to pull it out". I said "if you pull it out it will hurt, it's there for your comfort". (Interview 16)

The nurse was able to justify carrying out the procedure in terms of the good consequences it produced:

She's been fine with it since, but at the time she was saying "NO! I don't want it". (Interview 16)

The nurse's rationale for carrying out the catheterisation despite the patient's refusal was one of beneficence. She did not see any dilemma in carrying out the procedure. To the question, would she have done the same again, she replied:

Yes, definitely - no question. She needed it. I think it would have been negligent not to do it. If we hadn't catheterised her, we could have managed her - her skin was already sore - we'd not been able to go to her every 10 minutes and check that she's ... I think I was doing it because I know the risks of not doing it were greater than doing it ... I don't know, we needed to do it really" (Interview 16)

Although the participant acknowledged that the patient has a 'right' to refuse, this 'right' did not take on any significant weight in decision making. She was not prepared to let patient choice dictate nursing action - even if there was no question that the patient has the ability to make a valid refusal:

I suppose if you explain the risks to somebody and they are able to take on board and accept the risks of being uncomfortable, of still breaking down, of you know - it's up to them.. You can't forget consent because you do have to respect a person's wishes, but I think you can take a person's wishes into account - alongside the nurses' knowledge

and experience and also the patient's knowledge and ability to understand and accept responsibility (Interview 16)

In another incident, a patients' refusal of pain killers was eventually overridden by a charge nurse. Others nurses followed his example and administered the pain killers. In this incident, the competence of the patient to refuse can be questioned.

A lady with a fractured femur. She lived in a nursing home. She developed a way of attention seeking where she used to scream all the time. She refused- she refused whenever you moved her. You had to turn her but she screamed and said no no! Some staff would turn her anyway. Other staff wouldn't. She refused all analgesia. Some staff would give it, some wouldn't. It was a point of tension- some people would say she's said no but she's confused so we are going to give it to her anyway and she is in pain so it is our duty to give it. Others said but she's said no! and I'm not happy to give an injection when she's pushing me away. (Interview 16)

In this situation, the charge nurse took the lead on the approach to this patient's care and the other nurses followed suit.

the next day, the charge nurse said "I'm going to give this lady an injection" I said "but she has already refused... she insists she doesn't want one" he said "well I'm going to give it anyway" I checked it with him and he gave it to her...we had to move her into a side room because she was screaming all the time. (Interview 1)

The conversation with the participant explored whether she felt that the charge nurse had acted correctly. Her response redraws attention to the point expressed by an earlier participant.

... with specific problems you can't really generalise..there are no rules to follow (Interview 1)

Interestingly, this participant, consistent with the view expressed by the earlier participant, did not consider the principles of informed theory as useful guidance for managing such care situations.

The principle that whether a refusal is respected is dependent on the urgency of the care

situation was articulated by one participant in the critical incident interview.

H.A. Do patients ever refuse care?

Sometimes they refuse a dressing. Normally if its fairly intact, I wouldn't be so bothered, but if it isn't and they are feeling a bit rough or a bit tired, and say " please leave me alone " if its clean, we'll leave it. If it's oozing, and they are feeling a bit off, we'll leave it a bit, but it still gets done...

H.A. Does it get done with their consent, or reluctantly....

With their consent, as once you have described that they may get an infection, why it need s to be done, they are OK (Interview 22)

There is evidence that nursing care will be administered in the absence of a patient agreement if the care is considered to be essential. One reason for this may be that nurses find withholding care incompatible with their perception of themselves as nurses. The following conversation is illustrative of this. It does not relate to a described critical incident. The participant described:

If someone doesn't... (want a catheter) you have to accept it, but its hard and you know its not best for them. Someone who was really incontinent, and needed a catheter and they really don't want it, but if you can show them what you are aiming for, they must see light at the end of the tunnel. If they don't want it, you have to manage as best you can. (Interview 22)

Another participant commented on a situation in which a patient refused artificial feeding

...it was more difficult to understand... that throws up a lot of issues for the nurses. this is a woman who has quite reasonably made her own decisions, and they are actually completely opposite to what we would like to see happen...(Interview 6)

Despite the expressed recognition in the focus group discussions that the patient has a right to refuse care, there is no evidence that this right is acknowledged when practice is examined specifically. There is evidence that participants are not prepared to accept the refusal of a patient of a nursing care procedure if that procedure is considered beneficial; the patient's

refusal will be overridden. However further examination of the data in this thesis illustrates that the patient's refusal of nursing care may be overridden for reasons other than the implementation of what is perceived to be essential or beneficial care.

5.10 The patient who does not express his agreement to nursing care procedures. Care is administered for reasons other than clinical necessity

There is evidence that the patient's refusal of nursing care might be overridden for reasons other than clinical necessity. In the focus group discussions, many participants felt that restraints of time, routine and convenience contributed to a situation in which the patient's right to consent to nursing care procedures is not addressed. One group of participants discussed:

Sometimes you want to do it there and then for your convenience - not the patient's...

That's a big issue

But the best interests of the rest of the patients

You can't keep on changing the schedule cos someone says no, you've got ten others..

(Focus group 4)

The reasons for this were discussed:

The ward is a social place. It has its rules. Meals come at a certain time. If you're lucky...Practicalities have to override personal freedom ...

Rules in society - if a patient doesn't have a bath ... does that person actually have the right to say no in terms of the people around you - impinge on others?

(Focus group 4)

Two participants described specific examples of this in critical incidents. They described incidents in which nursing care was imposed in order that ward routine was maintained. In this incident, a mentally handicapped girl was forced into a bath before being transferred to another hospital :

A mentally handicapped girl who suddenly lost her mother., she then had behavioural problems and it was very hard to look after her..., when we changed her routine, it caused...she said she didn't want her bath in the evening (so she could go to a new home in the morning)..but we gave her a bath and she flooded me in the bathroom... it was her exhibiting her disagreement. I'm not consenting. I feel awful now for doing it...she had her routine and we disrupted it...it was sheer work organisation...

(Interview 20)

In another incident the reason for overriding the patient's refusal was also associated with ward routine. A lady who was suffering from chest pain, having been admitted the previous night was forced to have a wash. The incident was described by a nurse who witnessed the event:

The patient said she didn't want one - she was tired and wanted to sleep. It's actually very important that patients' wishes will be observed. We get very task orientated - between 8-12 midday, you will have a wash. I feel that that kind of consent is just as importance (as for surgery). The nurse said, well virtually, "bad luck, you will have one" and she proceeded to wash her. She protested all the way through. I asked the nurse afterwards why she felt it was particularly important that this patient had a wash and she said "we do all our washes between 8 and 12 - we don't like to hand them over to the afternoon staff" - I said she's not exactly smelly is she and she said "don't interfere" - I did feel quite badly for the patient". **(Interview 15)**

Finally, and less controversially, perhaps, two incidents were described whereby a patient refused an intervention, which was overridden due to safety considerations of staff and other patients. One patient refused to be lifted in a hoist:

We're all aware of how easy it is to be off work for months...we had a patient who was very heavy but refused to be lifted in a hoist...she'd fall over and wouldn't hold her weight,... we tried to stand her but we had to use the hoist as a last resort. I tried to explain to her that we were likely to damage ourselves... a balance between what the patient wanted and what was safe for us.

(Interview 4)

Another participant described an incident in which a patient's refusal was overridden for the sake of other patients. He consistently refused to have a bath:

He was admitted to the ward with mild dementia, you could have a reasonable conversation with him. He'd collapsed at home... medically he was quite fit and could go home but he had a lot of social problems.... He'd say he'd had a wash when it was quite apparent that he hadn't. He had such a strong urinary tract infection. It got to the point where the other patients in the bay were complaining about the smell. So it was quite a problem in itself and it was quite unpleasant for the other patients. (Interview 10)

The participant described the difficulty in trying to respect the patient's wishes (assuming that he was competent) while considering the needs of the other patients:

You tried to respect his wishes, perhaps he didn't want a wash, because we think its normal to wash every day, it doesn't mean that other people think its normal, so we tried coaxing him, but he'd still say he'd had a wash whenever you asked him. He'd say "I don't need a wash, I've already had one" but he was still in the same pyjamas since a week. (Interview 10)

In addition, the nurses had to assess whether the patient was in his right mind to make a decision:

I think he didn't want a bath, it was obviously to do with his dementia because he genuinely believed that he had had one. His dementia was only mild, but as he told these tall stories all the time, his dementia was very hard to assess. (Interview 10)

Overriding the patient's refusal when his refusal presents a risk to others is relatively uncontroversial. It is the principle upon which enforced detainment (although not treatment) of an individual under the public health acts are based. Commitment to this principle reflects the libertarian principles of Mill (1991) who asserts that an individual can experience freedom as long as this freedom does not impinge on the freedom of others. It is the application of this principle to nursing that requires interpretation. The extent to which the effect on others is measured requires quantification. It is permissible to enforce a bath on a patient because of the discomfort of others in his immediate environment, but not permissible, by the same reasoning to enforce a blood transfusion on the Jehovah Witness who is a mother of three young children, even if to do so would save her life and prevent her loss to the children.

5.11 The patient who does not express his agreement to nursing care procedures and this is respected.

Four incidents were described in which nurses respected the refusal of a patient. The characteristics of these incidents will now be examined. In the first incident, a patient was admitted following an attempted overdose. She refused intervention, but it was considered she would recover without assistance. The participant indicated that her refusal would have been overridden if treatment was considered essential. In a second incident, a patient who was suffering from pneumonia refused oxygen therapy. When questioned, the participant felt that in the circumstances, it was appropriate that the oxygen be discontinued:

This man had a chest infection which had turned to pneumonia. He was very poorly and was for T.L.C. (tender loving care)... he was kept on his oxygen and he got me during the shift and said "will you ring my family, take my oxygen off I'm going to die" ... and he died, it was just his oxygen that was keeping him going. It was his... he asked for that.

H.A. Did you feel that it was in his best interests that the oxygen was removed?

Certainly. (Interview11)

The participant was happy to respect the patient's refusal of oxygen therapy as this did not conflict with her perception of what were the patient's best interests. In further discussion, the relationship between the futility of an intervention and the patient's refusal was explored. The participant identified that if there was some potential therapeutic benefit to be gained from continuing oxygen therapy, the patient's refusal may not have been immediately respected. That is, the nurse did not express a commitment to respecting the patient's wishes *per se*, but only if these wishes coincided with what was considered to be in the patient's best interests; there was no perceived benefit to be gained from continuing with the therapy.

H.A. How would you have felt if it (the refusal) really hadn't been in his best interests?

I think he knew, you have to respect what the patient says and he obviously knew that his time was up, you could see that and we had to respect his wishes

H.A. Might it have been more of a struggle if death had not been so imminent?.

Definitely...we knew...

H.A. What do you think, as nurses, we should respond if a patient says "I can't take this oxygen anymore"?

It depends on his condition...if they need the oxygen, you are going to keep it on...this gentleman was for T.L.C...

It seems that the nurse was concerned to respect the patient's wishes - illustrating that there is some commitment to the principle of autonomy - but was only prepared to do so as long as these do not conflict with his best nursing interests.

In a third incident, a dying patient refused a naso-gastric tube. This refusal was upheld because there was no clear benefit to be gained from continuing the ng feeding. In a third incident, a patient's refusal of antibiotics for a severe chest infection was respected. In this incident, there is evidence that the clinicians felt that, again, it was in the patient's interests for her life not to be prolonged.

I had a lady who came across as quite intelligent but didn't have much understanding of what was wrong with her and refused to accept she had cancer. She had a chest infection and refused antibiotics as she felt that if she was on antibiotics, she wouldn't be able to go to the nursing home...I don't think they actually sat down with her and explained why antibiotics would be good and that they wouldn't stop her from going to the nursing home...that they would make her well enough to get to the nursing home. I don't know where she had got it from but she believed she wouldn't go...she refused the antibiotics on the Wednesday... On the Friday she agreed to have them .. it was another nurse, who talked to her...her chest deteriorated, she was bubbly and weakened..so we sat down and explained that it wouldn't get better without the antibiotics and she agreed to have them.... unfortunately it was too late..(the patient subsequently died)
(Interview 12)

In the fourth incident, a patient refused to be given suction from an unfamiliar nurse. The

participant was called to give suction to an unfamiliar patient (whose named nurse did not have the experience to do so). The situation had gone on for some time and the patient's breathing was distressed and bubbly. The nurse approached the patient:

I explained what I was going to do and he didn't say "yes that's fine" or "no it's not" but I went ahead and gave him suction in the back of his throat. It was clear that I needed to go down further. I took the suction catheter out and got a bigger one and he obviously hadn't had the experience with the other sucker. I explained to him why I needed to get the secretions up and that it would make him more comfortable and his breathing would be easier but he just firmly clamped his mouth shut ... he kept saying "no" he didn't want it. I tried explaining it several times because it was quite clear that he would be more comfortable and I knew he would be, .. he just said "no". I tried to explain it more slowly a couple of times - he just wasn't having it. I didn't do it. I thought, I'm not going to force it. (Interview 1)

The nurse acknowledged that failure on her part to explain the procedure might have contributed to the reasons for the patient's refusal:

I didn't know the patient very well. I just assumed that he'd been having regular suctioning and that he knew what would be coming. He probably had had suctioning before but he didn't quite understand - maybe I could have explained it better right from the beginning. I felt a bit frustrated - I didn't know the patient. I didn't know whether he'd had suctioning before. I assumed - made the assumption that he had....I would have explained things better from the outset, but I hadn't realised how all the circumstances were. (Interview 1)

The situation was resolved when there was a change of shift, and the patient agreed to the suctioning by another member of staff. We discussed whether it had been right not to force the patient to have the suctioning, despite the clinical indication for it:

I felt it was absolutely right - it was his right. I didn't want to invade his privacy. It was his decision. (Interview 1)

The patient's right to privacy (or freedom from unwanted intervention) was respected in a situation that was not immediately life threatening. We discussed whether, had the situation

been more serious, the nurse would have altered her actions. She implied that she would have done:

I don't think I could have left it much longer without having to do it. I'd hate to say that I would force it on him but maybe if I knew that was the only thing that was going to make him more comfortable then ... I don't know(laugh) . (Interview 1)

Again, although there is commitment to respect for the autonomy of the patient (the nurse was initially adamant that the suctioning could not be given without the agreement of the patient), the nurse's response indicates that respect of the patient's refusal was associated with the seriousness of the patient's condition. Her resolve to respect the patient's refusal by not carrying out the procedure, should the patient's condition deteriorate, was less determined.

There is a common theme to the incidents described in which the patient's refusal of nursing care is respected. The participants who described the incidents did not consider the care to be essential. All participants indicated that should the patient's condition alter so that care became essential, care would then be given. While care was regarded as not immediately necessary, they were prepared to accept the patient's refusal. This contrasts with the incidents described in the previous sections in which care was imposed, despite the non urgent nature of the care required. Thus, there is evidence that some participants are prepared to respect the refusal of a patient when the care is considered non-essential. However, none of the participants were prepared to accept the refusal of a patient whose care was considered essential.

There is one exception to this pattern however. One critical incident was described in which the refusal of nursing assistance by an independent patient was respected by the participant. For the patient's safety, she required assistance with walking. However, the participant acknowledged the patient's right to refuse such help. The participant described the tension she experienced in the situation. The lady had been in hospital before and felt she had lost her independence then. She was determined to retain it this time.

One lady who is so independent, she would rather be left or fall over than be helped. I tried to explain it was for her own safety and she did agree., I asked her to buzz when she needed to go to the bathroom. So she pressed the buzzer and was already up by the time I had got to her, grasping the end of the bed. I went to hold her arm and she brushed me away. I said "that's fine, I'll walk with you". She was OK with that. But

even walking alone she is unsteady and I feel that I have my arm always ready to catch her. But she wants to maintain that level of independence. From my point of view, I need to make sure she is safe.

(Interview 29)

The nurse described the tension inherent in the situation:

No, I am not.(happy)..She is so adamant, but I am adamant that she needs to be looked after. Sometimes she does agree... (Interview 29)

In this incident, the patient's refusal of assistance was essentially respected, but the participant made other consideration for her safety. To some extent, this incident marks a divergence from the principles identified in the data illustrated above. The participant allowed the patient to refuse essential care. She did however make alternative provision for the safety of the patient.

There is evidence that participants do not respect the refusal of a patient of nursing care, if that care is considered to be essential. No other studies specific to nursing practice have been identified in which a patients refusal of nursing care have been examined. However, failure to respect a patient's refusal was also identified by Holm (1997) who found that health care professionals were prepared to override the refusal of a patient if anticipated harm from withholding the intervention could be anticipated. Holm (1997) examined ethical problems in clinical practice in Scandinavia and described-

when the conflict occurs, and when the professional has decided that the harm is sufficiently significant to override the patient's wishes, various measures may be taken to 'persuade' the patient to do the right thing. Information can be given selectively, the patient can be 'threatened' or a decision may simply be imposed. (p129)

The data presented in this thesis reflects to some extent the conclusion drawn by Holm, that whether a refusal is respected is dependent on the considered urgency of the care in question. However this is not the whole picture. Consideration of factors other than the urgency of care was made by some participants. Some participants in the study were prepared to override the patient's refusal even when the care in question was not urgent. None of the participants were prepared to accept the patient's refusal when care was considered essential.

5.12 To what extent do participants respect the patient's refusal of nursing care?

Principle: The nurse should respect the patient's substantially autonomous refusal.

There is evidence from the data in the study that many participants are aware in theory that they should not proceed with a nursing care procedure in the absence of a patient's consent. This finding reflects those of Whalen (1984) as identified in Chapter 2. Some participants in the focus group discussion were adamant that a patient's refusal would be respected. Participants demonstrated that they are reluctant to proceed without the patient's agreement and would go to great lengths to achieve this. The principle that a nursing care procedure cannot be undertaken without the consent of the patient is also widely acknowledged in the nursing literature, (Murphy 1993), (Hunka 1993), (Longo 1993), (Robson 1994), (McGrath 1995) and (Toulson 1996). In a study of nurses' attitudes, Woodward (1998), participants expressed (although did not demonstrate) a strong preference for respecting patient autonomy even when to do so may not have been in the best clinical interests of the patient.

However, evidence suggests that this commitment to respect for a patient's refusal, (although not universally held) seems to be only theoretical. It may be one thing to express a belief about how informed consent and considerations of patient autonomy should be approached in clinical practice. It is another thing to put these beliefs into practice. There is evidence in this study that although some participants are aware that they cannot carry out a nursing care procedure until they have the consent of the patient, they are not prepared to withhold care. In practice, they are not committed to respect for the patient's refusal. Participants expressed the view that nurses' decisions to administer care were not altered by patient choice.

When the agreement of the patient is not immediately forthcoming, participants described how information is given which usually results in the patient's expressed agreement to the care proposed. However, it is argued that this expressed agreement does not necessarily signify the patient's consent. Whether or not the patient did signify his or her consent through this expressed agreement cannot be determined from the data obtained for this study. Participants suggest that this agreement is facilitated as the result of persuasion. However, given the seemingly irrevocable nature of the nurses' decision to administer care, it is suggested that persuasion does not accurately portray the influence put onto patients to accept nursing care. In Chapter 4, it is suggested that information is given to patients prior to nursing care procedures with which their compliance is not anticipated. Information giving thereby achieves compliance. There is evidence in this chapter that information is also given when patient

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compliance is not forthcoming. It is suggested that information is given until compliance is achieved. The voluntary nature of the expressed consent can therefore be questioned. It is indicated that the expressed agreement often achieved may merely signify the patient's compliance with nursing care rather than his or her consent.

Further evidence of the apparent irrevocable nature of the nurses' intention to administer care was identified when an expressed agreement to nursing care procedures was not achieved. In these situations, although participants expressed a *preference* for adhering to patient wishes they did not feel that these wishes should be respected if an intervention was clinically indicated. Consent can be described as desirable but not essential. None of the participants (with one questionable exception) were prepared to accept the refusal of a patient to nursing care that was considered essential. The non-administration of essential care was not perceived to be a viable option. While some participants were prepared to respect a patient's refusal of non-essential care, others were not. The irrevocable nature of the nurse's intention to administer care was not restricted to care procedures perceived to be essential. There is evidence that refusal of a nursing care procedure may not be respected even when to do so merely interfered with the ward routine. This suggests that nurses' reluctance to respect the refusal of a patient may not always be due to an (understandable) erring towards beneficence when life is at stake, or indeed even an erring towards beneficence at all.

This discrepancy between expressed knowledge and observed action requires further consideration. Evidence taken from a review of studies examining the ethics of clinical trials may shed some light, (Edwards et al. 1998). In one study reviewed, (Benson et al. 1991), 91% respondents expressed the view that consent should be obtained prior to participation in research; the majority of respondents were aware of the ethical and legal requirement to obtain consent. However, this did not concur with what was happening in clinical practice. In another study, Blum (1987) found that 85% respondents expressed their view that patients rarely understood the information given to them prior to enrolment in a clinical trial; hence negating the possibility for a meaningful consent. Thus although while on the one hand, many clinicians believed consent to be essential, they did not feel that it was achieved in practice. This reflects the data described in the present study; that while some participants expressed commitment to principles of patient refusal of nursing care, this was not reflected in their practice.

There are two possible explanations for this discrepancy between knowledge and action. Firstly, nurses might not agree with the application of the principles of informed consent. They

might not accept that care cannot be given without the consent of the patient; that ultimately 'caring for' patients should come first. Indeed one participant in a focus group discussion expressed this view:

The way the training is I think perhaps ... caring comes first .. what's good for the patient...perhaps it's different now

(Focus group 4)

Alternatively, nurses might not be aware how to apply the principles of informed consent when that consent is not forthcoming. That is, although nurses are aware that consent should be obtained, and that care cannot be given in the absence of a consent, they do not have a working understanding of how these principles can be applied when difficult situations are encountered.

Indeed, the logical application of informed consent demands that care cannot be given in the absence of a patient's consent; that the patient's refusal should be respected. However, many writers leave room for the discretion of health care practitioners to guide their practice. Beauchamp and Childress (1994) do not specify which of their four principles should take priority when two or more conflict (as identified in Chapter 1). Holm (1997) acknowledges that although paternalism is an outdated concept in modern health care, there may be times when its application can be appropriate.

although there is agreement in ethics that paternalism is a bad thing, there is still disagreement as to whether it is always a bad thing . That the ethical framework described here leaves room for paternalism is not necessarily a sign that there is something fundamentally wrong with the framework, as long as the room left is small
(p157)

McCormack (1998) advocates that a benevolent approach is appropriate in certain clinical situations, although he does not specify which.

there are of course other times when a firm approach has to be taken and sometimes without this firmness, the person would feel insecure and at risk (p345)

McCormack does not state which circumstances, in his view, warrant this firm approach. However, to adopt a 'firm approach' to the enforcement of nursing care implies that the

patient's reluctance or refusal can justifiably be overridden. McCormack does not indicate that a 'firm approach' should be taken only with patients who are unable to make their own decisions. This absence of a prescriptive approach may contribute to uncertainty as to the application of the principles of informed consent.

Application of the doctrine of informed consent necessarily requires that a patient cannot be given care to which he or she does not consent. To give care in the face of a patient's refusal is to reject the doctrine of informed consent. In Chapter 1 it has been argued that an informed consent does not have to be fully informed to be valid; it must be 'substantially' informed. The same principle can be applied to a refusal. A refusal will be valid if it is 'substantially' informed, in other words, if it represents the substantially autonomous choice of the patient.

The participants in this study were not committed to the principle that a patient's refusal, if sufficiently autonomous, should be respected. Not surprisingly, therefore did they show any attempt to assess the autonomous nature of a patient's refusal. None of the participants in the study initiated discussion of whether the patient was sufficiently autonomous to refuse care; whether the refusal amounted to a valid refusal. When the autonomy of the patient was discussed, there was a strong tendency to imply that the patient was not in possession of sufficient facts or understanding to make a valid refusal. Interview 26 clearly illustrates this point. On all occasions, this discussion on this point was initiated by the interviewer, not by the participant. The idea that the patient is *never* in possession of enough facts or understanding to make a valid refusal is strongly represented in the discussion. This strict criteria of understanding is not reflected in the literature concerning informed consent as described in Chapter 1. The participants in this study did not demonstrate a working understanding of the principles of informed consent when a patient refuses or is reluctant to accept nursing care. Participants did not consider the non administration of nursing care to be a viable option. However they justified this by reasons other than by questioning the ability of the patient to refuse care.

To withhold nursing care in the face of a patient's substantially autonomous refusal is not uncontroversial. It may be one thing to require that patients give their consent prior to certain nursing care procedures, as discussed in Chapter 1. It may be another thing to follow this requirement through to its logical conclusion and require that care should not be delivered without the patient's consent. Indeed the many examples cited in this chapter indicate that to withhold care is, for whatever reason, unpalatable to those who participated in this study. It

certainly does not seem to be a part of nursing culture to allow a patient to refuse care. However, informed consent theory, as reinforced in legal rulings as discussed in Chapter 1 affords the patient the right to refuse care. If informed consent is to be applied in nursing practice for the protection of patient autonomy, then it should be applied with consistency. Application of informed consent theory prior to nursing care procedures requires that the valid refusal of a patient should be respected.

In Chapter 4, the way in which consent prior to nursing care is regularly assumed was described. Sometimes, but not always, this assumption will be justified under the web of expectation that surrounds health care procedures. However, justification of any care under the web of expectation, must, by definition, incorporate the patient's easy opt out of that care. Unless it is possible for patients to opt out of care, it cannot be argued that the web of expectation exists. In the focus group discussions presented in Chapter 4, participants claimed that patients should opt out of care they did not wish for. This was suggested in defence of the situation described, that consent prior to nursing care procedures is largely assumed. However, there is no evidence in this chapter that it is easy or indeed possible for patients to opt out of care. Nurses' intention to administer care is apparently irrevocable; participants did not consider not administering care to be a viable option. As a result, patient attempts to opt out of care were largely blocked. The patient's right to refuse care was consistently ignored by those who participated in this study.

Bullet points: The patient who is reluctant or refuses nursing care

1. Most participants are aware that they should not proceed without the consent of the patient.
2. However they are not aware how to proceed when the patient's consent is not forthcoming.
3. There is no evidence that participants made an assessment as to the validity of the patient's refusal.
4. When the patient did not immediately agree to a procedure, participants were persistent in information giving; much effort was given to securing the patient's eventual acceptance of the procedure.
5. Use of persuasion is compatible with the ethos of informed consent
6. However, there is evidence that unacceptable pressure was sometimes exerted onto patients in order to achieve their compliance.
7. Nurses' intention to administer care is apparently irrevocable; it does not depend on patient choice.
8. Participants expressed only a preference for obtaining the patient's consent. Consent is desirable but not essential..

6 CHAPTER 6: THE PATIENT WHO IS UNABLE TO CONSENT

6.1 Data included in this chapter

Inductive analysis of 103 critical incidents identified 43 incidents in which the care of a patient who is unable to consent to nursing care procedures was the main happening. A further 8 incidents were identified in which nursing care of a patient who was unable to consent involved the administration of sedative drugs or restraint. These incidents are discussed in this chapter. These data are reinforced by exploratory data contained in 11 units of analysis from the focus group discussion. This data provides evidence of how consent is addressed when the patient is unable to consent. Some of these data are presented and discussed in this chapter.

6.2 Nurses are uneasy about giving care

One main theme to arise from the critical incident data was the unease experienced by many participants when they had to care for a patient who could not consent. One participant described an incident in which she was called to another ward to look after a critically ill patient whom she had not met before. The participant was uneasy about carrying out a procedure on a patient with whom she couldn't communicate:

one patient had had a stroke, in heart failure, had a tracheostomy, he was aphasic. he couldn't talk to us... he was not breathing well, he had c.p.a.p. (continuous positive airway pressure) and oxygen, everything... he became more unwell. At about midnight,... I listened to his chest. We knew his heart wasn't functioning that well.. we gave him plain humidified oxygen...the thing I found most frustrating was that I couldn't communicate - he looked so distressed and he didn't know me from a bar of soap. Obviously I spoke to him...but he couldn't respond and he looked terrified and I found that very hard and we were continually doing things to him (Interview 18)

The participant indicated that her unease at carrying out the intervention without the ability to communicate effectively to the patient was exacerbated by the unfamiliarity of the patient:

...I felt that if I had only known him for longer, it would have made all the difference, someone the patient knows - the patient feels known...you know what they like and what they may want..._more importantly, I would have known how to speak to him...his background. I had nothing to go on. (Interview 18)

She questioned whether she should carry out a procedure even though it was clinically indicated, because the patient was unable to consent to it. She was unsure how to proceed.

I realised he was still very dry and I had to decide whether to put some saline into his trachea...to facilitate suction of secretions. I knew I had to do something arguably nasty to this man. I couldn't get his consent. What was I to do? In the end I decided to do this, but it was a big hurdle, that he would have to experience something nasty. I did it. I told him about it, but that hopefully it would help him, he continued to look frightened. He didn't respond to anything, he just looked frightened. I found it very difficult. I did it and it worked...on balance I felt it was the right thing...but he couldn't tell me and he couldn't tell me that he was grateful. (Interview 18)

The participant discussed how, in her view carrying out an unpleasant nursing care procedure on a patient who cannot agree to or understand what is happening, felt like a violation of the nurse patient relationship. The participant, an experienced practitioner, was clearly uncertain how she should proceed to give care to a patient who was unable to consent. The patient was ultimately given the care that was in his best interests but she did not reach this decision with conviction. It might be implied that the participant's concern about carrying out an invasive procedure on a patient who is unable to consent was exacerbated by uncertainty about the established principles for caring for a patient who cannot consent.

I don't think I could have done anything different...arguably you could not do anything, but then he might have died, risking his life because he can't consent doesn't help...the answer is I don't know what the answer is...I tried everything I could in terms of telling him.... (Interview 18)

Finally, it is interesting to consider whether it is the patient's lack of understanding or his lack of consent to the proposed procedure which seems important here. The participant is concerned that the patient is unable to understand what is happening. This indication reflects the emphasis of the data in Chapters 4 and 5, in which participants were concerned that patients were informed about forthcoming procedures, rather than that they gave their consent.

Another participant described the unease she experienced when caring for a patient who could not consent.

One patient who is confused and they had to do a lumbar puncture on her. Obviously you couldn't get consent from her as she was so confused. they had to sedate her as she was so agitated...it's hard, very hard_ what we ask her to do, she can't do, she can't keep still. We try and explain, but we find we just keep doing things to her, there's no way she can tell you. We explain what we are doing but we don't know whether she understands...or whether she wants something done. It's hard as you just have to do it.

H.A. Does she resist at all?

No she's very placid in some ways..putting ventflons in. If you hold her hand she'll keep her arm still, but other than that she is so agitated, she won't let you do much to her really...placid but agitated....its very awkward... hard, very hard, frustrating. It's not very nice doing things to patients when they don't understand. Their arms are everywhere. It doesn't seem like a protest it, its just how she is.... (Interview 22)

Again, there is evidence that the difficulty experienced by staff at caring for patients who cannot consent is exacerbated by lack of a working understanding of the ethical and legal principles of consent which should guide practice. The participant indicated her uncertainty about the appropriateness of the action they had taken.

you know you are not doing anything....this is probably wrong.. harmful..we are genuinely trying to help... it helps when you are trying to help...we've had quite a few agitated....you try and explain things and you try and explain and they are not having anything.. (Interview 22)

In both these incidents, the participants carried out the nursing care that was clinically indicated but they were not assured that they were doing the right thing. They seriously doubted whether they should carry out the care at all. They appeared unaware of the principles that should guide their practice. The nurses felt that care should be given, but could not rationalise why.

In two further incidents, the participant was aware how they should proceed when a patient is unable to consent, but still found it difficult to do so. One participant described how she felt uneasy about carrying out nursing care on a patient who is unable to consent. The participant described her unease in terms of the lack of opportunity for the patient to refuse.

We had to put a catheter into this lady, it was vital that we did so, she didn't understand what I was doing...its difficult because had the lady been able to express how she was feeling, she might have refused it... I always think she may still have refused it... you do feel that you are going against her will... she didn't put up any objection, but she knew I was doing something undignified by what I was doing... so it's difficult... (Interview 5)

In this incident, the participant's unease was associated with her concern that the patient may have refused the intervention had she been able to. However, in the participant's view, there had been no option but to put in the catheter. She was aware that she had a duty to act in the best interests of the patient and felt that this might have been facilitated if it had been possible to contact the next of kin. This incident had occurred at night and contacting the family had seemed inappropriate.

Just when you are faced with a person, you've got to take that decision yourself, what is in that patient's best interests... it's what you do. (Interview 5)

Another participant described, in general terms, her unease at caring for a patient who is unable to consent:

In a high dependency unit, confused after surgery. A lot of what you do, you need to do for the patient's safety. If they have lots of lines going in, it's very difficult with confused patients. There are occasions you do things that the pt doesn't want doing but need them done. You just need to think that it is in the patient's best interests. It's very difficult. Its usually quite transient.. a few days later they are better. I would only do things that really needed doing for example, if they needed their blood pressure checking, if they are on drugs. If you don't want it done, you have to get on and do it and if they won't let you, you have to have someone help you (Interview 21)

There is evidence that some participants in this study felt generally uneasy about giving nursing care to a patient who is unable to consent. This unease sometimes caused participants to waver in their conviction to give care. This unease may be exacerbated by a lack of knowledge of the principles that should guide practice, but is still present when nurses are apparently aware of guiding principles. In all the incidents cited above, the patient did receive the care that was in his or her best interests, despite the uncertainty of the care giver. That is, participants wavered

in their approach to care giving to a patient who cannot consent, but ultimately the appropriate care is delivered. In the following incident, the unease experienced by the nurse portrayed leads to her refusal to give care.

A participant recounted a situation in which a member of staff refused to carry out a nursing procedure that was clinically indicated because the patient was unable to consent.

A lady - who I had known from previous admissions with liver disease - had come in with hepatic failure. She needed three enemas daily and the newly qualified nurse who was looking after the patient and she refused(to be given the enemas) because the patient was so 'flat' she couldn't give consent at all (Incident 17)

Although the participant felt that this was probably wrong , she could not articulate why.

Certainly the first time I had actually had to think about it. My justification was - well I know the lady, I know this is what she would want even though she isn't able to consent at all. So I felt quite justified in saying that if we don't do it we are going to end up with more problems. It was quite difficult and the first time I had been in a situation where I had had to think about it. In a lot of ways I could see her reasoning behind - enemas are quite - but what choice do you have with an unconscious patient (Incident 17)

This incident is interesting in that neither the nurse described nor the participant relating the critical incident demonstrated a working awareness of the principles that should guide practice when a patient is unable to consent. Both were unsure on what justification it might be permissible to administer the enema to an unconscious patient and indeed were prepared to authorise non treatment. For the nurse who took part in the incident, this failure to administer care in the best interests of a patient who could not consent could indeed be negligent.

Interim discussion

Unfortunately there is no focus group data to provide further insight as to why participants felt uneasy about giving care. Furthermore, no other empirical evidence has been identified that examines the nursing care of patients who are unable to consent. However data collected for this study includes a set of critical incidents in which participants recounted incidents in which sedation had to be administered to an aggressive patient. These incidents are summarised in

Appendix 6. They are not included in the main body of data as they do not relate specifically to the administration of nursing care. However, the administration of sedation was met with immense unease by participants who recounted the incidents.

The critical incidents reviewed in this section demonstrate the unease that nurses experience when they give care to a patient who cannot consent. The reasons for this sense of unease are purely speculative. One cause of nurses' unease may be a lack of awareness of the legal and ethical principles to guide practice for those caring for a patient who cannot consent. This was evident in some of the incidents described, but not all. Some participants were clearly unaware that they had a legal duty to proceed with care that was in the best interests of the patient. Others were aware of this duty but still felt uneasy. However the depth of their awareness cannot be ascertained. They may have held a vague awareness, insufficient to amount to a conviction that care should be given. There are various indications that health care practitioners' knowledge of how to proceed with care for patients who cannot consent is sketchy. This has been evident to the author through the course of giving many seminars on informed consent to qualified nurses. In addition, Bhatti et al, (1998) found that health care workers knowledge of mental health legislation to be limited.

Another cause of the participants' unease about caring for a patient who is unable to consent may be that participants are uneasy about administering care when they are unsure of the most appropriate care to give. When the patient is unable to authorise care, or choose from a variety of possible options, the nurse has to take responsibility for authorising that care. Absence of the patient's authorisation in this instance means that the nurse has to rely on her own judgement alone, which might be a cause of unease if she is at all uncertain about that judgement, or indeed, whether it is appropriate for him or her to exercise that judgement.

There is evidence that participant's unease is exacerbated when the intended intervention is unpleasant. Some participants described concern over carrying out an unpleasant procedure on a patient with whom they could not communicate. Participants were concerned that to implement care was a violation of the nurse – patient relationship. They were concerned that the patient would not agree to the procedure if they were able to communicate. This concern may have been exacerbated by lack of a working understanding of the principles that should guide practice when a patient is unable to consent. This lack of understanding in turn leads to a lack of conviction that the care proposed is the appropriate course of action.

It is interesting to note that unease about carrying out a nursing care procedure without the consent of the patient is not wholly consistent with other data in this study. Evidence from the data presented in Chapters 4 and 5 demonstrate the participant's only moderate concern to obtain the consent of the patient prior to a nursing care intervention. When faced with the choice of proceeding with an intervention or respecting the choice of the patient, there is evidence that many participants will proceed with the intervention, even though they would prefer to have the patient's agreement. However the overriding sense of unease about proceeding without the patient's consent, evident in this chapter, is not evident in the previous two chapters.

The participants in this study are clearly not confident about providing care for patients who cannot consent. However the reasons for this lack of confidence are not clear. The unease demonstrated by nurses is important because it causes doubt as to whether care that is in the patient's best interests should be given. Nurses' unease about caring for patients who cannot consent is therefore a threat to the provision of nursing care. The incidents reviewed in this section are relatively straightforward; that is, they are not complicated by factors such as the apparent resistance of the patient or the relatives to the provision of care. In the absence of complicating factors, most participants did provide the required care, despite feeling unhappy about doing so. For the purposes of this study, this set of circumstances is described as the default position. In the following sections, nursing care situations are examined in which complicating factors are present which cause the participant to waver from the default position of care giving when a patient is unable to consent.

6.3 This unease is exacerbated when the patient appears to resist.

In this section, the administration of nursing care is challenged by the apparent resistance of the patient, who is unable to give a meaningful consent, to the proposed care. In the first incident, members of a family and health care professionals could not agree on the care that would be in the best interests of a patient who was clearly unable to make her own decisions.

A lady came in with a stroke. She'd been fit and well prior to that, she was fairly old, mid 80s and there was a complex family history, she was separated from her husband who was very clingy throughout the admission, and had some grown up children.. She didn't have any means of communicating with us, it came to the question of nutrition as it often does and the doctors decided they wanted to pass a naso-gastric tube We talked to the family with the doctors. The children decided they wanted the patient to

make the decision if she could, but the husband wanted us to push ahead and do it anyway. (Interview 14)

The participant described her unease at caring for a patient who could not indicate her wishes:

For me it was the first time - I hadn't been qualified long- I had encountered something that ethically.. where I was very uneasy... it was difficult, we weren't forcing things on her against her express wishes, we just didn't know what her express wishes were... I guess consent almost becomes...it doesn't become irrelevant, but you've almost got to have some sort of ethical framework to decide whether to treat that patient, and that's an ethical minefield... (Interview 14)

Unable to resolve the difference of opinion as to what constituted the best interests of a patient, the staff adopted an alternative approach in determining the best interests of the patient. They returned their attention back to the patient - whom they had initially considered to be unable to make her own decisions - and decided that they would interpret her nonverbal communication as an agreement or disagreement to the proposed intervention.

We then spent the next couple of days trying to get something out of her. Occasionally she'd nod, but you could never be absolutely certain she'd consented to something. We explained it to her but we didn't get any definite signal that it was OK to do it, we didn't get a definite signal that it wasn't either... so in the end we decided, with the whole family that we would pass an naso-gastric tube and if she didn't want it she could pull it out, so one was passed and within a few hours she'd pulled it out, which was, by the original agreement, we'd taken that to mean she didn't want it to be in. (Interview 14)

Having agreed to let the reaction of the patient determine the provision of care, when presented with a course of action that the staff and family found unacceptable, they reviewed this position. As the incident ran its course, the staff fluctuated in their opinion as to whether they felt that the patient's nonverbal signals were a representation of her true wishes.

The husband then said that she wasn't capable of making that decision...and that it was an accident that she'd pulled it out...he pushed for it to be put in. The rest of the family didn't take it as a dissent, they didn't take it as a no, the nursing staff thought, we began to get uneasy about it at that stage, the medics wanted to try and pass it

again, I don't think anyone felt strongly that she had refused the treatment by pulling it out.

We passed another one and she pulled it out and at that stage the nursing staff decided that it was that she didn't want it, the medical staff still wanted it in ... but we and the children decided that she'd had a go and wanted to have a go...eventually the medical staff agreed with us that she didn't want the ng tube, but sometime later,, a week later, she ended up having a peg tube in, again, the husband managed to bring the family round to seeing that they were giving her another chance, she had it put in and three days later, she died of a chest infection. (Interview 14)

The participant ultimately rejected the idea that the patient was able to express any consent through nonverbal communication:

She may have been completely confused and not understanding.. you would never know if it was informed dissent... but all we could know is that she'd pulled it out. we cant extrapolate that to say she'd understood everything we'd said...you cant really take it that far. you are left with limited information.

It is interesting to note how the staff viewed the interpretation of the patient's nonverbal signals. It may be one thing to be guided as to what the *best interests* of a patient are according to his reaction to a clinical event, although, as this incident illustrates, it is doubtful whether this may be helpful. It is another thing to interpret these gestures as evidence that the patient is consenting to or refusing the procedure. However, the language used by the participant to describe the incident indicates that she felt that these signals may be interpreted as the patient's consent or refusal to the proposed care, not as an indicator of what the patient's best interests may be. For example - "...staff agreed with us that she didn't want the ng tube" and "the family didn't take it as a dissent"

The participant described another incident in which a patient resisted catheterisation, following a stroke:

She was unable to talk, she was really quite flat,.she ... it was a matter of catheterising her without obtaining consent....she was so flat that she wasn't able to consent. I explained but she wasn't able to.give any indication that she'd understood what I

meant... (Interview 11)

Again, the participant toyed with the idea of interpreting the patient's gestures as a consent or refusal of care, but they ultimately proceeded with the catheterisation, as this was considered to be in the best interests of the patient. On reflection, she was not sure they had done the right thing:

this is what we did and this is probably wrong, I'd only thought of it after I'd spoken to you..we just held her hand out of the way and catheterised her. I guess we were making the decision for her, she was trying to keep us off, but we were saying "we need to do this, it's good for you.." ...although we interpreted the hand as dissent....pushing us away. It depends if you interpret it as dissent or as a reaction to a painful stimulus, a reflex, the lady was completely flat. I'm pretty sure she was just responding to an unpleasant stimulus....that was my interpretation....it's not consent is it.....I know that's paternalistic but as I say in similar circumstances I would probably do the same thing again... (Interview 11)

The participant felt that she had probably done the wrong thing as she had done something against the 'will' of the patient. She was not confident that being 'paternalistic' - acting in the best interests of the patient - was the appropriate way to care for a patient who cannot make her own decisions. It is interesting to note the participant's use of the term paternalistic. Most ethical theorists argue that it is only possible to be paternalistic to a patient who is competent to make her own decisions. Acting in the best interests of a patient who cannot make her own decisions is not normally referred to as paternalism, (Feinberg 1986).

The participant justified how she felt it was in the best interests of the patient to have a catheter:

In the long run, we were saving her more pain by catheterising her, the potential problems of pressure sores, but again it was someone who wasn't able to give consent.....when the catheter is passed, its going to be unpleasant in the short term...but in the long term, save pain further down the road, but not necessarily extend her life... if she gets a raging UTI or septicaemia, it could even shorten her life.. (Interview 11)

In this situation, the participant did not act according to the patient's gestures because to do so would not have been in the best interests of the patient. On consideration, the participant felt that no real weight should be placed on the interpretation of the nonverbal communication of the patient.

This time I decided that I would ignore that gesture, whereas the time before I thought the gesture was more in accordance with what I was thinking. (Interview 11)

In the two incidents described by the participant, staff involved in the care of the patient who could not consent deliberated whether to be guided by the non verbal signals of the patient. The participants were clearly uncertain how they should interpret the non verbal communication of the patient. They were tempted to regard these non verbal signs of the patient as representative of his or her consent rather than just the reaction to a stimulus. The patient's response to the stimulus can be interpreted in terms of a first order desire; that is not evaluated, as per Dworkin's definition as described in Chapter 1(1988) (p108). Ultimately they decided against carrying out care according to these unevaluated non verbal signs, but they did not come to this decision easily. Eventually, care was given that was in the best interests of the patient. They were unsure on whether they had taken the right course of action.

The tendency of staff to try to interpret the gestures of a patient was discussed in many other incidents:

A person who has had a stroke, who can't swallow ... there is a communication problem and you are not sure if they really understand or not... they don't understand. You put a naso-gastric tube down and they keep pulling it out and it reaches a stage when you think " are they saying I want this out or are they pulling it out because it is irritating"...people read into that ...they say they are taking it out because they don't want it in, whereas I don't think they don't necessarily want it in... (Interview 1)

To give another example:

I had a patient who was unconscious. All she would do is smile and cry... it was very difficult _she had been fed for 5 years when she came to us.. the tube kept coming out, and she kept rubbing her nose on the pillow, as a sign she didn't like the tube and within a month we had put another sort of tube in. Just our different perspective...we

were able to find an alternative way to feed her it might have been just...she didn't mind the tube. But we felt she did. (Interview 20)

The participant described how staff usually proceed with the nursing care intervention, despite the apparent resistance:

Sometimes you get a bit of resistance, you don't know whether they want to be left alone..an encephalopathic patient, drowsy, sleepy, he resisted care.. body arches, he was very difficult to move. That could be a subconscious "no" he doesn't want to be moved... but can't verbalise it. (Interview 20)

The participant acknowledged the possibility that the patient may be indicating some resistance to care, but did not feel that it amounted to a refusal that should be respected. Her reaction was to:

Get on and quickly wash the patient, instead of thinking "this is a sign of resistance". You think that if they were aware that they were incontinent or sweating, they would want us to do that but you don't know... (Interview 20)

Generally, staff reported that they would carry out the nursing care procedure that was in the best interests of the patient who was unable to consent, despite the apparent resistance of a patient. However, there is evidence that they were unhappy about doing so, and were not unaware of the principles of informed consent that would justify this action.

Often we do put tubes down against a patient's will, if we are unaware of their wishes...if the patient pulls the tube straight back out, so you do it again and they pull it out and you don't know if its an automatic reaction, for a foreign body... or whether they really don't, and if they really don't want the tube, where do we stand? (Interview 11)

The understandable tendency is to err on the side of caution:

So often you have to assume that they want to be fed. To assume they don't want to be fed is too huge...if someone has had a massive stroke and is very poorly, then it probably isn't in their best interests...to feed them. But if someone has had a stroke and

you are not sure what they understand, what they want, we must assume they want to be fed. (Interview 11)

While there is evidence that most nurses will give the care that is indicated to a patient who cannot consent, despite his or her apparent resistance to the care, the following incidents highlight that this will not always be the case. One participant described a patient who resisted catheterisation. The procedure was abandoned because, due to the resistance of the patient, they could not get near her.

a confused lady . she didn't respond appropriately to questions.. it was quite difficult. she was so confused didn't know what was going on... who was incontinent and we wanted to catheterise her. Her skin was breaking down, it involved a lot of turning. we decided to catheterise her- for her own good, comfort, but she couldn't rationalise it. You would explain it to her but you knew she didn't really understand what you were saying, you had to explain it to her, but she didn't really know what you were saying, so she was pushing you away and she kept calling out no no no! and we abandoned the attempt. She's just thinking of her immediate...she had such limited sensory stimulation. The only stimulation was that she was going to be manhandledobviously it was uncomfortable for her but you couldn't rationalise it with her. (Interview 1)

The procedure was halted. At interview, we discussed whether the transient distress of the patient outweighed the longer term benefits of catheterisation.

Yes...yes. the distress was a transient one, the distress at being wet all the time is longer lasting... so it's difficult. I stopped because I didn't feel happy she was getting quite agitated about it. There was no point in continuing.

H.A. Would you have been happy about somehow forcing catheterisation on her?

I think that is why I stopped because I didn't feel happy she was getting quite agitated about it. There was no point in continuing...I think you need to try but I think I was right to stop.. she .. it was distressing (Interview 1)

In this incident, the resistance of the patient was not interpreted as a sign of refusal which they

should adhere to, but a physical barrier to carrying out the procedure; the distress for the patient was too great. However, another participant described how she would not be happy to carry out a necessary nursing care procedure if the patient, unable to consent, protested.

If they could protest, I wouldn't do it

H.A. Even if they needed it?

No....also you can't say that as he was confused he can't make any decisions... but you can't measure how much confused someone is...

H.A. Would you be happy to allow a patient who was confused to refuse something, even though with your knowledge, he needed it.

The man (who resisted the naso-gastric tube) .. if he hadn't drunk the feed, I don't know what would happen. We'd have had to try again with the tube, get the family to have a talk and explain why he needs it. At the end of the day, you can't measure confusion and you cant make him have it... (Interview 1)

Interim discussion

There was no data from the focus group discussion to shed light on how nurses respond to a patient who seemingly resists a nursing care intervention. Furthermore, no further empirical evidence was identified in the nursing literature. The patient who, although he cannot consent, seemingly resists nursing is the cause of further anxiety for participants. While most participants demonstrated that they would ultimately adopt the 'default position', and give care to a patient who apparently resisted it, they were uneasy about doing so.

The patient's resistance presents a complicating factor to the participant which exacerbates his or her unease about giving care. While participants are uncertain whether and on what grounds they should proceed with care when a patient cannot consent, this uncertainty is exacerbated when the patient demonstrates some signs of resistance. Any tentative resolution to proceed with care when the patient cannot consent is shaken by the patient's resistance. Many nurses contemplate whether they should interpret the resistance of the patient as a refusal of care, although, on reflection at interview, they mostly reject this approach.

In the previous section, it was suggested that unease at carrying out a nursing care procedure without the patient's consent is due to a lack of conviction on the part of the nurse that this is the right thing to do. If participants do not understand the principles of consent, they are not assured that to administer care that is in the best interests of the patient is appropriate. Furthermore, misunderstanding of the principles of consent might lead participants to believe that the patient's resistance does signify some sort of refusal. The patient's resistance serves to exacerbate this lack of conviction that to give care to a patient who cannot consent is appropriate. Again, while most nurses do proceed with care, there is evidence that some do not. The consequence is that there is no guarantee that the care that is in the patient's interests will be carried out.

6.4 The unease is exacerbated further if relatives resist.

In this section, relative involvement in the administration of nursing care to a patient who is unable to consent is examined. The resistance of the relative to the proposed nursing care is another complicating factor in the care of a patient who cannot consent to nursing care.

In three critical incidents, relatives did not challenge the administration of care, but participants felt that they should have had greater involvement in the care. One participant described an incident in which the relatives of a patient had not been informed about the catheterisation of a patient. The patient had had a stroke and was unable to communicate. She reflected on the way in which care had been given.

The doctors decided..(that the patient needed a catheter) the nurses put it in , the family were informed after it was in....this same lady, she had an ng tube and that was discussed with the family before. I don't see why they couldn't have done the same with the catheter...I think feeding is like, actively treating whereas a catheter isn't...but I felt that they should have tried to contact the family. But if they were getting incontinent all the time and the family weren't able to be contacted..if they couldn't find the family they have to get on and do it.

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H.A. Why do you think we should tell the relatives? Out of courtesy or..

Yes, out of courtesy it's an invasive procedure..

H.A. If the relative refused to let you do the naso gastric tube or the catheter, what

would you do?

It would depend on who the relative was, some are very close, others are distant, you would have to make sure you knew who the relative was and did they have the best interests at heart. If they refused you would talk to the relatives and explain why it had to be done. (Interview 27)

In the participant's view, it is courteous and good practice to contact the relatives. Another participant expressed the same viewpoint.

We've got someone who is dying at the moment. He couldn't ask about morphine, or a catheter and so we've discussed this with the wife...if he was in a lot of pain, then we would do it without telling her, because it would be in his best interests...in an ideal world it would be nice to have someone there....but you have to act in the interests of the patient. (Interview 27)

Another participant expressed similar views:

A lady who is unconscious. She needed a new naso-gastric tube. I didn't ask the husband, he wasn't there. I couldn't ask her as she was unconscious. If the husband had been there I would have asked him, but probably said what I was going to do rather than could I do it (Interview 26)

The participant implies that to have said 'could I do it' would have been advantageous. The participant implies that ideally, consent should be obtained from relatives prior to a nursing care procedure, although in this case, she did not think to do so:

I presumed that he knew why we were putting down the ng tube and why she needed it so I presumed that he would agree to it. His wife, although she is unconscious, we are expecting her to regain consciousness. We aren't treating her as if she is terminal. I didn't think to wait to ask the husband, presuming that he'd say to go ahead as it was for her benefit. (Interview 26)

The way in which the family should be involved was discussed:

I think consent is important. I think ...the problem is whether you involve the family, it would take such a long time...in a way it is presumed that you trust the medical profession to do what is best and if you were to ask them every time...obviously the decision to start naso-gastric feeding, we are going to discuss that, major change in treatment , or any problems, but there is a problem if you want to discuss every venflon. (Interview 26)

The participants were concerned to involve the relatives in the care of the patient. However, it is unclear whether they felt they had a duty to do so (and thereby to obtain the relative's consent) or whether they wanted to consult the relative out of courtesy. In these incidents, the relatives did not demand that a specific action be undertaken. In the following incidents, relatives were more demanding. In these incidents, participants in the study expressed uncertainty about the way in which relative preferences should be considered in the care of a patient who could not consent. In the following incident, there is evidence that relative agreement to the procedure was considered not merely courteous, but essential. The participant described an incident in which staff and relatives disagreed on the care that should be given to a patient.

We had one lady who was very constipated and needed frequent enemas and the family would not let us give anything without their consent...she'd had one on another ward and had been quite ill. They wouldn't let us give any enema at all without their consent. It was quite difficult, we felt we wanted to intervene and it was for the patient's interest and you try to explain it... they did eventually agree...but we weren't allowed to do it unless we'd explained it to them first... we felt they were getting in the way. We knew what we were doing was in the patient's best interests and they were obstructing that...(Interview 7)

The family eventually agreed to allow the nursing staff to give the patient an enema; but after three days of the enema having been withheld. The participant was unsure the extent to which the views of relatives should be followed.

I suppose with those (confused) patients you have got to... I don't know... you never think about these things do you? You have to go with the relatives to some extent....(Interview 7)

In another incident, the agreement of the patient's wife was considered to be essential to the administration of care. A participant described a situation in which the wife of a patient refused nursing care 'on behalf' of her husband who was unable to consent. Instead of acting in the best interests of the patient and carrying out the nursing care procedure that was clinically indicated, they deferred the decision to the patient's wife.

A patient had had a profound stroke, it had affected his speech, he couldn't make his wishes known.. and his wife was a nursing sister and she very definitely didn't want a catheter inserted (Interview 9)

As a result of respecting the wishes of the wife, the patient became uncomfortable. The wife still opposed any nursing intervention.

he got very very excoriated because of the urine.. In the end , he was on the ward for months - to my knowledge he never had a catheter.. he got very excoriated he had pad and pants which I felt was very degrading for him.. he was a grown man, having to be in a nappy...but when he wasn't sore, he'd got a conveen on and it worked reasonably well no matter how bad he got, his wife was insisting "no I don't want a catheter put in" (Interview 9)

This situation is complicated further in the fact that the wife was not merely putting forward her views as to the best interests of her husband. She claimed to know what her husband would want in the situation; declaring that her husband would not want a catheter inserted.

his wife was adamant he didn't want a catheter inserted... we respected that decision, we tried with conveens... (Interview 9)

The nurses did not carry out the procedure that, they considered, was in the best interests of the patient because of the demands from the patient's wife that he would not have wanted a catheter:

She knows what her husband feelings are. I have mixed feelings whether it was a good or a bad thing... The staff were very angered, a poor situation that they (the wife and the patient) were putting themselves through this. What have they got against a catheter?.. it would make his life so much easier. No one really forced her hand one

way... one or two people felt this "is ridiculous". Why don't we just put a catheter in...it's for his comfort. it was decided that we can't really do that. It shouldn't be a case of us deciding for somebody, it's still their body at the end of the day (Interview 9)

The legal status of anticipatory decisions is now well established in the courts. It is generally held that a specific advance refusal of treatment will be as binding to the practitioner as a refusal not made in advance, if certain conditions are met, (Grubb 1994). However, if there is significant doubt as to the validity of these advance proposals, they will not be legally binding to the practitioner.

The staff involved in this incident were prepared to accept the wife's demands. The participant discussed the incident as though in his view, the wife had the right to consent on behalf of her husband.

Although it was, from a consent point of view, it was really well observed... we wouldn't argue with this woman anyway, she knew her husband and she felt he would not want that. We just abided by her decision. In some respects it was wrong because of the suffering and discomfort he went through, but it was still his decision... he nodded his assent throughout.

H.A. How would you manage it if it happened again?

I think I would manage it in the same way.. there's nothing... if someone was very adamant they didn't want it in, I'd explain the pros and cons, but the decision they've made at the end of the day "if you don't want a catheter were not going to put a catheter in" (Interview 9)

In the participant's view, the relative was better placed to determine the best interests of the patient than were the clinical staff. He implies that the relatives should take responsibility for the clinical decision as opposed to merely providing guidance in identifying the best interests of the patient.

It's fair enough for them to make the decision. They know the relative, we don't I would follow the relative's wishes on the whole....if they were dead set against it, I

don't think I would actually go against that...I would just say "this is your decision."
(Interview 9)

In another incident, a participant described a situation in which the relative objected to the decision which had been made about care for his wife. In this incident, the decision had been made not to resuscitate an elderly patient. The husband objected to this decision.

One relative's wish was overridden and that was over a resuscitation order. A lady who'd had a profound stroke.... we spoke to the husband and said that if her heart was to stop we wouldn't want to do anything... We don't think it would help... he just said "I want it done, if her heart stops, I want everything done.". We told him it would cause her untold pain and in all probability we wouldn't get her back, it was 8-9 weeks down the line and there was no improvement... and this man was greatly aggrieved, I don't know whether he did make a complaint, but he was talking about it. It was very odd situation on the ward... the decision was that it was right, we would never get her back, she'd had such a dense stroke... everybody on the nursing staff was relieved that in the end this decision was taken out of our hands ...we'd been trying to chip away a little at a time, saying "do you really want your wife to suffer?" (Interview 9)

We discussed the extent to which the relative should be involved in decisions about resuscitation.

In one respect I still believe it is the right of the husband to say, "I want my wife resuscitated"

H.A. Even if its not clinically indicated>?

Even if it's not clinically indicated... I understand his right to say that

H.A. Why does he have a right if all the medical evidence...?

I know... I know...(pause) it's a gut reaction. I know how I would feel but I don't know how I would react...knowing how much I feel for my wife and not wanting her to die... (Interview 9)

Although this decision was not directly a nursing decision, the implications of it affected the nurses involved. Again, the staff were uncertain how the decision should have been taken.

We felt where do we stand? I would have preferred that the decision had come from the husband. From an ethical standpoint, it's difficult to understand how the doctor can take that right away from the relative. . I can see why he did, but from a moral point of view, it wouldn't have been right to resuscitate. but ethically where we stood with the duty of care....? (Interview 9)

This confusion is illustrated by the discussion held by one articulate group of participants in one of the focus groups. They did not demonstrate an understanding that consent is only appropriate when a patient has the ability to do so. Interestingly, these perceptions were unchallenged by other group members, indicating that none were aware of the misinformation.

The scenario of son giving a verbal consent - staff nurse signed form. "Where would we stand if something went wrong?"

If you've got a patient who can't read and write - you get an 'X'.

But then you've got the difficult situation of unconscious patients . . . who would sign then. Situations that arise would be so many . . . could you sign just in case the need arises for example prior to surgery, but I can see the need for it.

(Focus group 4)

Interim discussion

When the patient is unable to consent to nursing care procedures, relatives may become involved in decisions about their nursing care. The involvement of families in the patient's care is generally a welcomed and established part of nursing practice, (Buchanan, A.E. & Brock 1989). However it is essential to establish the boundaries of such involvement where issues of consent prior to nursing care procedures are concerned. At the time of writing, it is clearly established that no one can consent or refuse care or treatment on behalf of an incompetent adult. A relative does not have the legal power to consent to any care procedure on behalf of the patient. Whether or not the procedure is undertaken remains a clinical decision; responsibility is not given to relatives. Where confidentiality permits, it is courteous to keep the relatives informed about the patient's progress. Furthermore, relatives may be consulted as to

what care they consider to be in the best interests of the patient. There may be disagreement. Ultimately however, health care professionals have a duty to act in the patient's best interests and the responsibility for providing appropriate care lies with the health care professional.

At the time of writing, there are various suggestions for changes in legislation that would introduce the concept of proxy decision making into English health care practice. This would give legal right to a named proxy to make decisions on behalf of the patient who is unable to consent. However, such suggestions have not yet been implemented. The principle guiding practice for the care of patients who are unable to consent remains that they should be treated in their best interests. This decision should ultimately be a clinical decision.

On most occasions when caring for a patient who cannot consent, participants were keen to involve relatives, but they did not feel an obligation to do so. This is in accordance with present guidelines for caring for patient who cannot consent. However, in these instances, the relatives were not asserting themselves to be involved in decision making. Although some participants were unsure how much weight to give to the concerns of relatives, in the absence of relatives' opposition to care, the observed default position was that patients were given the care that was considered to be in their best interests. However, when the relatives became involved in the decision making process and objected to the proposed care, the participants' conviction that care should be given was again shaken. Participants wavered in their resolve that care should be given. Instead, the approach to care giving was guided by the demands of the relatives, although there was some uncertainty as to whether this was an appropriate course of action.

The influence of relatives in decisions about nursing care was observed by McCormack (1998). In his study, he observed what he described as the 'professionalisation of relatives' whereby nurses attached a disproportionate significance to the views of relatives and indeed acted according to these views. He observed that "*relatives views, wishes and perspectives were acted upon at the expense of the patient*" (p258)

McCormack observed this disproportionate weight given to relatives' views in comparison with the views of the patient himself. He commented: .

I find it strange the way in which the opinions and views of relatives are given precedence over those of the patient themselves. While it is important to consider the views of relatives, I find it hard to accept that the relatives should be treated as 'always

right' and the patient as 'always wrong'. It seems as if the nurses are unable to challenge the perspective of relatives or are afraid to do so for fear of consequences. It appears to me that relatives are treated as fellow professionals (p258)

In the present study, the relative's views were in discordance with the professional opinion of the nurses responsible for the care of the patient, as opposed to the views of the patient him or herself. However, the same tendency as observed by McCormack is present in the data for the present study; nurses attached greater significance to the views of relatives than their own professional opinion as to what they considered to be in the patient's best interests.

The tendency for participants in this study to bow to the demands of relatives demonstrates the weakness of the so-called 'default position' – that care will be provided in the patient's best interests when he is unable to consent. The participants' lack of conviction about the provision of nursing care is illustrated by their unease with which they do carry out care and the ease with which they can be diverted from the provision of care that is clinically indicated. On occasions, this leads to the acquiescence to relative's demands, even if these are clearly not in the best nursing interests of the patients. The result of this acquiescence to relative views is critical: nursing care, considered to be in the best interests of the patient may be withheld because of the opposition of the relative.

6.5 Are patients who are unable to consent given cared for 'in their best interests'?

Principle: The nurse should not seek consent from those patients who are unable to give it. The patient should be cared for in his or her best interests.

Clearly, not all patients will be able to give their consent prior to nursing care procedures.

No matter how much information they are given and how non-coercive the situation, (some patients) cannot give a valid consent because they are incompetent to do so. (Culver & Gurt 1982) (p53)

According to Buchanan and Brock (1989) (p80-81) ascertaining the patient's status with respect to competence is of utmost importance because it determines the primary locus of decision making authority. The competent patient is the primary decision-maker regarding his or her own care: legally and ethically the competent patient has the right to accept or reject any form of care or treatment. The incompetent patient does not. It is therefore essential that nurses

are able to assess whether the patient has the ability to consent.

There is some evidence in this study that participants are making this assessment; patients whose decision-making abilities were impaired and therefore unable to make decisions were identified in critical incidents. However it is not clear how this assessment was made.

In general terms, the threshold at which a patient is considered able to make his or her own decisions is low. That is, most patients will be able to do so. Buchanan and Brock (1989) (p80-81) discuss this threshold:

with the exception of certain classes of patients who are clearly incompetent, such as the comatose, the severely demented or the severely retarded, as well as younger minors, patients are to be presumed competent unless there has been an explicit and documented determination of incompetence (p81)

Despite recommendations that health care professionals develop strategies to assist in the assessment of those patients who cannot give a valid consent, (Jackson 1994) (p53) and (Buchanan, A.E. & Brock 1989) (p47), no evidence was identified to suggest that such skills are being developed by practitioners. The assessment of the validity of a patient's consent or refusal was not mentioned throughout the period of data collection for this study.

The participants in this study were not working with a defined concept of a threshold for determining a patient's ability to make his or her own decisions. Decisions tended to be made on an individual basis, at the discretion of the individual nurse. One common attitude, for example, was for a patient to be considered unable to make his or her own decisions if the decision was out of line with what the nurse would have preferred to see. That is, participants in this study commonly set a very high, rather than a low threshold for decision-making ability.

When a patient is unable to consent, current ethical and legal standards demand that he or she be cared for in their best interests. However, there is evidence that participants are not confident that care can be carried out in the best interests of patients who are unable to consent. They are not assured that they are proceeding correctly when they administer care to a patient who is unable to consent. In the absence of any complicating factors - when neither the patient nor relatives present any apparent resistance to care, the data suggests that most participants are prepared to give the required care. This has been described as the default position and might

merely be a reflection of the natural tendency for nurses to act with beneficence towards their patients (Chapter 5).

The conviction to administer care to a patient who cannot consent is easily shattered. When an objection to the provision of care is perceived, participants' uncertainty how to proceed is increased. Participants waver in their resolve to carry out the care that is clinically indicated. Instead, there is a tendency to view the objection as a refusal of consent. That is, there is a tendency to look for consent where none is required. Some nurses are tempted to interpret the non-verbal signals of a confused patient as a sign of consent or refusal, although, on reflection this is usually rejected and care is eventually given. When the resistance comes from the relative, it is less easily overcome. Usually, the patient does receive the appropriate care, but in certain instances, they do not. That is, care is not always provided that is in the patient's best interests.

A paradox emerges when the data from Chapters 4&5 are referred back to. In these chapters, participants described how they would prefer to obtain the patient's agreement prior to a nursing care procedure. However, they were prepared to go to great lengths to achieve this agreement and did not appear to reflect on the quality of that agreement. Furthermore, there was much evidence to suggest that participants regarded this agreement as preferable but not essential. Although participants preferred to obtain the patient's agreement, the contemplation of, or indeed procedure of, nursing care in the absence of a patient's agreement did not elicit the unease as described in the data for this chapter. It appears that there are times at which proceeding without the consent of a patient is the cause of more unease than at others.

The following paradox emerges. If informed consent principles are adhered to, it could be expected that participants should experience unease at proceeding with a care procedure in the face of a patient's refusal, given that the principles of informed consent demand that a refusal is respected. Such unease was not overtly evident in the data collected for this study, as documented in Chapter 5, although that is not to say that it is not experienced. However proceeding with a care procedure that is in the best interests of a patient who cannot consent is in line with informed consent principles and might therefore be expected to present the participant with less unease. In this study, participants experienced unease at administering care to a patient who could not consent. It is suggested that participants' unease in administering care is not directly related to the lack of informed consent. Participants did not demonstrate great unease when faced with the possibility to administer care to a patient who had previously

refused to consent. It is suggested that unease in administering nursing care is more closely associated with the participant's own lack of conviction or confidence about the proposed procedure. This conviction may be influenced by the agreement of the patient or the opposition of a relative. It is likely to be influenced by the participant's knowledge of informed consent theory. When the participant did not have a working knowledge and understanding of informed consent theory, his or her conviction that appropriate nursing care can be administered is weakened.

Nursing care appears to be administered to patients who cannot consent by default rather than by design. That is, in the absence of complicating factors, care is likely to be administered in the patient's best interests. However this is thrown into jeopardy when complications arise. Participants in this study did not have a strong conviction that nursing care should be administered to a patient who is unable to consent.

Bullet points: The patient who is unable to consent

1. There is no evidence how participants assess the patient's ability to consent to nursing care procedures.
2. Participants are uncertain how to proceed when a patient cannot consent.
3. Most participants are prepared to give care to a patient who cannot consent, but are uneasy about doing so.
4. The resolve to give care is shattered if the patient or relative appear to resist the intervention.

7 CHAPTER 7: TO WHAT EXTENT DOES THE CONCEPT OF INFORMED CONSENT INFORM NURSING PRACTICE?

7.1 Introduction

In this thesis, the application of informed consent theory prior to nursing care procedures is examined. In Chapter 1 it is argued that consent is required prior to nursing care procedures as advocated by the U.K.C.C. (1996) and again by the U.K.C.C. (2000). However, given that the purpose of consent is to protect the patient's autonomy, consent is required prior to those procedures which threaten the patient's autonomy. These procedures, will be individual to each patient. What is significant to one patient may be insignificant to another. Furthermore, the quality of the information required to facilitate the patient's consent will vary according to individual need. The requirement for obtaining consent prior to nursing care procedures should be determined by the patient rather than determined by the health care professional. This ethical obligation to obtain informed consent according to individual patient need exceeds the legal obligation to obtain consent..

In Chapter 2, the literature concerning informed consent prior to nursing care procedures was examined. No evidence was found in the nursing or related literature concerning how consent is obtained. Furthermore there was little discussion about consent prior to nursing care procedures. Discussion focused on the nurses' role in facilitating consent prior to non-nursing care procedures. Thus, although there is a strong argument in favour of the application of consent prior to nursing care, this has been barely addressed in the literature. Review of the literature indicated that the concept of consent prior to nursing care is largely undeveloped. In view of this, while it can be argued that consent in nursing is appropriate, there is no evidence concerning its application. The appropriate application of informed consent principles prior to nursing care procedures requires careful consideration.

This study sought to examine the way in which consent is obtained by nurses prior to nursing care procedures. There were two aims of the study. First, to examine how consent is obtained prior to nursing care procedures. Second, to explore the ways in which consent could be approached by clinical nurses. In this thesis, two methods of data collection were used to examine how consent is obtained prior to nursing care procedures. Exploratory data were obtained through focus group discussion and more specific reporting of practice was obtained through the use of critical incidents. While there were some deviant cases, as identified in Chapter 3, strong patterns emerged through the process of data analysis so that ultimately the

two different types of data collection pointed to the same overall findings. These findings are summarised below.

7.2 Main findings of the study

There is evidence that consent prior to many nursing care procedures is not obtained; it is assumed. Care procedures are often carried out following minimal or no explanation to the patient. Most of the evidence suggests that consent is assumed because of patient compliance. It is unclear whether this was a willing compliance. Certain nursing care procedures were accompanied by information giving. These tended to be those prior to which the patient's compliance was not anticipated. Information giving was associated with the need to achieve compliance with a care procedure, as opposed to obtaining the patient's consent.

There is evidence that many participants were aware that a nursing care procedure should not be administered if the patient refused such care. Some participants were adamant that a patient's refusal would be respected. Most participants demonstrated a reluctance to proceed without the patient's agreement and would go to great lengths to achieve this. When a patient was reluctant to undergo a nursing care procedure, information was given. While this is often appropriate, there is evidence that information was given to constrain rather than facilitate patient choice and therefore incompatible with the ethos of informed consent. In this study, participants were usually successful in facilitating the patient's expressed agreement, although the extent to which this was freely given cannot be determined. It has already been suggested that information is given when patient compliance is not anticipated. It can also be suggested that information is given when patient compliance is not forthcoming.

When the patient's agreement could not be facilitated, many participants were not prepared to withhold nursing care. Nurses' intention to administer care is apparently irrevocable; not dependent on the patient's choice. A commitment to "getting the work done" above all else was found in an early study of pre-registration nurses by Melia (1987). This commitment is still evident in this study. Such a commitment is clearly at odds with commitment to the principles of informed consent.

Participants expressed a preference for adhering to patient wishes, however they did not feel that these wishes should be respected if an intervention was clinically indicated. The concept of choice in patient care was not upheld. Consent can be described as desirable but not essential. None of the participants (with one possible exception) were prepared to accept the refusal of a

patient to nursing care that was considered essential. Furthermore, the seemingly irrevocable nature of the nurse's decision proceed with care, irrespective of the wishes of the patient was not restricted to care procedures perceived to be essential. There is evidence that refusal of a nursing care procedure may not be respected even when to do so merely interfered with the ward routine. This suggests that nurses' reluctance to respect the refusal of a patient may not always be due to an (understandable) erring towards beneficence when life is at stake, or indeed even an erring towards beneficence at all.

When the patient was unable to consent, many participants lacked assurance that they could proceed with the nursing care that was in the best interests of the patient. In the absence of any complicating factors - when neither the patient nor relatives present any apparent resistance to care, most participants are prepared to give the required care, although they demonstrate great unease at doing so.

The conviction to administer care to a patient who cannot consent is easily shattered. When an objection to the provision of care is perceived, participants' uncertainty how to proceed is increased. There is a tendency to regard the objection to the provision of nursing care from the confused patient or from the relative as a refusal of consent which should be respected. In most cases, the patient does receive the appropriate care, but in certain instances, they do not. That is, care is not always provided that is in the patient's best interests. Nursing care to a patient who cannot consent appears to be given by chance than by recognition of guiding principles.

The participants in this study did not demonstrate a working understanding of the principles of informed consent that could be applied to nursing practice. However they demonstrated some awareness of a concept of consent. This awareness influenced their approach to patient care. They were aware, for example that care should not be administered if the patient overtly refused such care. However when the refusal could not be resolved they were prepared to proceed with the administration of nursing care. Likewise, participants were not assured that they could proceed with nursing care when the patient was unable to consent. They would falteringly do so, but were troubled that consent had not been sought and wondered whether the objection of a relative should be interpreted as a refusal of consent. Furthermore, none of the participants in the study initiated discussion at interview about the ability of the patient to consent to nursing care. Participants were working with some concept of consent that informed their practice, but this concept did not reflect principles of informed consent theory as defined in Chapter 1.

7.3 Trustworthiness of the study

The aim of this research was to obtain a description and explanation of nursing practice concerning the way in which consent is obtained prior to nursing care procedures. In Chapter 3, the optimal method of obtaining this picture was discussed. Obtaining consent prior to nursing care procedures is a complex activity which may not be easily observable or measurable. It has been argued that the constructed accounts of clinical nurses concerning the way in which consent prior to nursing care procedures might achieve greater insight into the complexities of nursing practice than a positivist approach. Positivist and post-positivist research paradigms were rejected in favour of an approach that focused on the realities constructed by those involved in the study. It was suggested that while constructed accounts are necessarily subjective, they may lead to insights that are a closer account of 'reality' than those obtained by more objective approaches, which may fail to elicit insight into the process of obtaining consent prior to nursing care procedures.

This study has presented the constructed accounts of the way in which consent prior to nursing care procedures is obtained. These accounts were constructed in individual interview in the examination of specific critical incidents and through focus group discussion. Lincoln and Guba (1985) define four criteria by which the value or trustworthiness of constructed inquiry can be assessed. These are credibility, transferability, dependability and confirmability, (p301-331). The way in which each criterion applies to the present study was examined in Section 3.3.23. The author can confirm that the processes of data collection and analysis as described in this section were adhered to rigorously and systematically in order to enhance the trustworthiness of the study. The inevitable bias brought by the individual perspective of the author, discussed in Section 3.3.9 can be acknowledged but not eliminated.

7.4 Consent prior to nursing care procedures is an undeveloped concept.

Despite the acknowledged limitations of the study, the emerging picture to arise from the process of data analysis is strong and consistent; participants did not observe the principles of informed consent when they undertook nursing care procedures. A commonly used expression by participants in this study was that consent prior to nursing care procedures is assumed. It is not considered and it is not obtained according to principles of informed consent as outlined in Chapter 1. Even when consent could not be assumed because the patient refused care, the procedures were often undertaken.

There is evidence that informed consent as advocated by nursing professional bodies is not realised in practice. This lack of application of the principles of informed consent in practice is well documented in previous studies of ethical conduct, (Green et al. 1996), (Bhatti et al. 1998) and (Edwards et al. 1998).

However the reasons for the lack of application of the principles of informed consent in nursing practice require specific consideration. Nursing policy documents and literature consistently emphasise that nurses should obtain the consent of their patients prior to undertaking a care procedure. This is discussed in Chapter 1. The idea that informed consent theory should apply to nursing care procedures is rarely challenged. However there is little further discussion of the way in which consent prior to nursing care procedures should be sought. That is, the concept of consent in nursing is an undeveloped concept.

Examination of the empirical and non-empirical nursing literature provides further evidence that the concept of consent in nursing is undeveloped. There is very little research or discussion in the nursing literature concerning the nurses' role in facilitating consent prior to nursing care procedures. In Chapter 2 it was hypothesised that this lack of attention to consent prior to nursing care procedures in the nursing literature may reflect a lack of attention to consent prior to nursing care procedures in clinical practice. This hypothesis is supported by the findings of this study in two ways. First, as identified above, the overall picture obtained from the data clearly indicates the lack of attention given to informed consent prior to nursing care procedures. Second, the attitudes and perceptions of many participants reinforced the idea that informed consent in nursing is not a concept that many were familiar with.

These attitudes and perceptions are demonstrated in various ways in the data. For example, some participants had not considered that informed consent was required prior to nursing care procedures. They considered that the principles of consent applied to medical or research procedures but had not considered that informed consent was relevant to nursing care. This participant's comment was typical:

when (the ward manager) asked me to help with your study, I had never thought about informed consent to nursing. (Interview 27)

Lack of familiarity with a concept of consent prior to nursing care procedures was apparent

when participants described how they applied the principles. Principles of informed consent were applied in a vague and haphazard way, inconsistent with the principles of informed consent described in Chapter 1. Many participants in the study were aware of the concept of consent and were concerned to incorporate the concept of consent into their day to day practice. However, when they described how they did so (in the critical incidents and through focus group discussion), it became clear that the concept of consent was vague and poorly understood by many participants.

Another participant reiterated the assumption that informed consent is associated with medical tests and surgical procedures, not nursing care procedures:

we are good at talking to patients about tests and operations, reinforcing the medical side of things, but we are not so good at the nursing side. (Interview 20)

Other participants perceived the principles of informed consent as inappropriate in nursing. They perceived the principles as a rigid formula, which required the patient's signature on an official form. They did not perceive this formula to be appropriate to nursing care procedures. The following participants' comments were typical:

Basic nursing care, interaction with patient ... some of the basics ... on a basic level. You know, giving the patient a wash, that would be a ridiculous situation ... to have to sign a form... (Participant in Focus Group 2)

In this study, consent was strongly associated with a signed consent form. Participants did not demonstrate an appreciation that a consent form is merely evidence that consent has taken place. They regarded a consent form as an integral and essential part of the consent process, without which the patient's consent could not properly be obtained.

It is often stated that written consent is neither sufficient nor necessary for a valid consent. Kennedy and Grubb (1994 p95) argue:

Consent is expressed when the patient explicitly agrees to what is proposed by the doctor. It need not have been set out in any specific form and it need not be in writing.

The written consent form merely provides evidence that consent has been obtained. This

evidence may not even be very strong. This was expressed by Bristow J in the case of *Chatterton v Gerson* (1981)

It (a signed consent form) would be no defence to an action based on trespass to the person if no explanation had in fact been given. The consent would have been expressed in form only, not in reality. (at 265):

It is not the intention here to negate the role of consent forms in health care per se. The production of a consent form may serve to raise awareness among staff that consent is necessary. The form may help them to approach the patient. It may help to ensure that consent is obtained. Prior to some nursing care procedures, a written consent form may be appropriate. However it is not an essential element and would be inappropriately used prior to all nursing care procedures. This was clearly articulated by the participants in this study. It is indicative of the participants' lack of understanding of consent that they associated obtaining a patient's consent with signing a form.

Participants' perception of consent was also revealed through the language used to describe consent in nursing. This was evident in the language used by participants and apparent throughout the data. The following example is an illustration of this. The participant describes how the opinion of the patient's relative is used to determine care given (this critical incident is discussed in more detail in Chapter 6). The participant was concerned to honour the principles of consent in his management of the situation, and was unaware that he was not doing so.

no matter how bad he got, his wife was insisting "no I don't want a catheter put in" although it was a poor situation, (but) from a consent point of view, it was really well observed...(Interview 9)

There is much evidence to suggest that informed consent was so poorly implemented by those who participated in this study because consent is an undeveloped concept in nursing practice. There is no concept to be implemented. This is suggested in the literature and is apparent in the data. Consent in nursing has not been subject to debate and discussion within the nursing profession. The potential ambiguities have not been addressed and resolved. Some nurses are not aware that consent is a relevant concept in nursing. Those who are, are uncertain about how it should be applied. When they attempt to apply the principles of informed consent prior to nursing care procedures, the principles are often applied in a haphazard misinformed way.

It seems that principles other than those of consent influence nursing practice. It was often indicated that an ethos of 'caring' rather than consent dominates nursing practice. Several participants expressed this view.

I personally would say that I do and think well your here to be cared for, for us to do what needs to be done,(Participant in Focus Group 6)

I don't see why we shouldn't give care if we know that will benefit the patient.(Participant in Focus Group 2)

*The way the training is I think perhaps ... caring comes first .. what's good for the patient...perhaps it's different now
(Participant in Focus Group 4)*

The data presented above gives further evidence that nurses are committed to the administration of care, as identified in Chapter 5 but not within the context of informed consent. This is further indication that the concept of consent is yet to be developed within nursing.

7.5 Developing a concept of informed consent prior to nursing care procedures.

A concept of consent prior to nursing care procedures is required. Nurses need to develop an understanding of the principles of informed consent which can be applied specifically and appropriately to the context of nursing. Nurses should recognise that nursing care procedures have the potential to infringe patient autonomy and embrace the concepts of patient choice and the facilitation of substantially autonomous choices prior to nursing care procedures. This concept should ensure that patients are given the opportunity for meaningful decision making with the context of nursing care and that they receive appropriate care when they are unable to choose. In this chapter, an application of informed consent theory prior to nursing care procedures will be developed and discussed in the light of the data generated in this study. The aim is to develop an understanding of informed consent that is relevant to nursing practice and is accessible for nurses to use.

Informed consent should be understood as a means of protecting and enhancing patient autonomy. The significance of autonomy and the potential for its infringement should be

acknowledged in nursing care. Furthermore, the patient specific nature of potential infringements of autonomy should be acknowledged. There is evidence in this study and in the literature cited in this study that informed consent is often associated with a limited set of predefined procedures and the requirement for written consent. Informed consent is therefore often considered to have little relevance to nursing care procedures. The importance of the protection and enhancement of patient autonomy prior to nursing care procedures should be acknowledged. This is acknowledged by the U.K.C.C. (2000) who, in the development of competencies for nursing practice, state that nurses should:

formulate and document a plan of nursing care where possible in partnership with patients, clients, their carers and family and friends, within a framework of informed consent (p15).

Furthermore, the specific requirement of consent prior to nursing care procedures is endorsed by the U.K.C.C. (1992), who reinforce a nurse's accountability for practice. Consideration of professional accountability clearly reinforces the necessity to consider consent prior to a nursing care procedure rather than to assume that consent is not necessary or has been obtained elsewhere.

A concept of consent is required which is relevant and applicable to the context of nursing practice and the individual values at stake. The following principles are applicable to seeking informed consent prior to nursing care procedures. These principles are derived from the principles of informed consent theory as discussed in Chapter 1. They have been applied to nursing care procedures after consideration of the main themes identified in the examination of the practice undertaken for this study. However they are principles which require the appropriate application in practice. This application requires further study, which is beyond the scope of this thesis.

7.5.1 Principle 1: The initial offer of information

Nurses should approach all aspects of care giving with the expectation and willingness to discuss the care procedure with the patient. Initial information about what the patient should expect about the procedure should be given to the patient. This initial use of information is a means of identifying the importance of a procedure to an individual patient. If the patient shrugs the information off or appears uninterested, the nurse can deduce that the procedure is not important to the patient and further information is not required. In this way, the patient is

not subjected to unwanted provision of information.

The assumption that a care procedure can be carried out without giving information to a patient is one of the most fundamental observations of the practice described in this study. Many participants described how nursing care procedures are carried out with no explanation. There is evidence that this was unacceptable to some patients in this study. Furthermore, it is argued that nurses should be wary of assuming that the patient's compliance represents his or her implied consent. The initial offering of information ensures that the acceptability of a particular care procedure to a patient is not assumed. For example, the patient with a religious objection to a bed bath is given the opportunity to express an objection to the care proposed.

7.5.2 Principle 2: The further exchange of information

Following the initial offer of information, information should be given in as much detail as the patient requests – and as is available in published evidence or other rationale, as discussed in section 1.5. Given that evidence based practice is not available about all nursing care procedures, information will not always be available. The nurse should be aware of the extent to which his or her practice is research based and be prepared to explain this to the patient. The nurse should be prepared to discuss rationale for the care, the expected benefits and possible harm. If the patient requests further information or resists the procedure, it is reasonable to deduce that the procedure is important to the patient. The nurse can then give further information as it is requested and assist the patient in the evaluation of that information as discussed in Chapter 1, until the patient is able to authorise the procedure or to withhold his or her authorisation.

Many participants in this study described how information is often not given to patients. Meanwhile, they associated the process of informed consent in nursing with a need to give minute detail about every care procedure. They perceived it to be a rigid procedure, associated it with the signing of a form. They were therefore sceptical of its relevance in nursing, dismissing the idea as too time consuming and unnecessary. This move towards a patient centred approach to information giving prior to nursing care procedures integrates the current ethos of patient centred care in nursing (Ersner 1996) (Titchen 1996) into the principles of informed consent.

7.5.3 Principle 3: Implied consent can be considered valid if it is obtained following information giving.

The term implied consent should not be used to describe all aspects of care giving which prior to which explicit consent is not obtained. Implied consent is a valid form of consent prior to nursing care procedures. It is argued that implied consent is valid if the patient has been informed about the procedure in the manner described above. If the patient is offered as much information as he or she requires and is thereby sufficiently informed to make a meaningful decision, has the opportunity to opt out of the care, and implies his or her consent, then implied consent can be considered to be valid. Implied consent differs from verbal or written consent only in its expression. The patient does not have to express his or her consent verbally or in writing. Implied consent is expressed through implication.

Many participants in this study described incidents in which they perceived a patient to have given implied consent which, on closer analysis was more likely to have been compliance. This is discussed in Chapter 4. It is likely that nurses were assuming the patient's implied consent. Given the difficulty in determining whether a patient's behaviour signifies an implied consent, it is argued in this thesis that nurses should not assume the patient's implied consent. Instead, information should be offered prior to all nursing care procedures in the manner outlined above. If the patient then does not raise an objection to the procedure, his or her implied consent can be considered valid.

7.5.4 Principle 4: Information to facilitate meaningful decision making

Nurses should give information to facilitate patient choice rather than patient compliance. There is evidence in this study that many participants used information giving as a means of achieving patient compliance with nursing care procedures. Information was often given during a procedure, rather than before. Patients were *told about* the procedure rather than given the opportunity to consent to it; that is, the consent aspect was denied to them. They were not given the opportunity to opt out of care. This finding reflects the findings of other studies, (Levy 1999b) and McCormack (1998). Nurses should review their attitude to information giving. Nurses should seek to give information to patients in such a way as to facilitate their genuine agreement to the care proposal.

7.5.5 Principle 5: Persuasion should be employed properly.

If a patient is reluctant or refuses to undergo a nursing care procedure, this reluctance should be acknowledged and managed sensitively. The procedure should be discussed with the patient

and further information offered if requested. Clearly, the nurse has a duty to advise the patient about optimal care. This has been referred to as 'protective steering' and is discussed in Chapter 5. The nurse also has a duty to investigate why the patient is reluctant or refuses a care procedure. Sometimes reassurance or persuasion may be all that is required to reverse a patient's reluctance. The use of persuasion is appropriate if used as defined below.

the intentional and successful attempt to induce a person, through appeals to reason, to freely accept - as his or her own, the beliefs, attitudes values, intentions or actions advocated by the persuader (Faden and Beauchamp 1986) (p347)

Persuasion entails that the patient freely accepts the care procedure. Information should be given to facilitate this free acceptance.

Participants in this study described unacceptable pressure exerted on patients to ensure their compliance with care procedures. There is a fine line between persuasion, properly employed and unacceptable pressure on a patient to accept a procedure. It is argued that the difference between the two lies in the nurse's attitude to the administration of care. The aim of persuasion is the patient's free acceptance of a procedure rather than the patient's reluctant acceptance of a procedure, following unacceptable pressure. Persuasion entails choice. If nurses appreciate this, this may guide the way in which they approach patients who are reluctant to undergo a procedure. Nurses should move away from an ethos in which care giving is considered to be the only inevitable course of action and employ the use of persuasion to ensure that unacceptable pressure is not exerted on to patients to comply with care regimes.

7.5.6 Principle 6: Decision making should not be subject to the unwanted influence of others

Nurses should ensure that the patient's decision making is not subject to the unwanted influence from others. In addition to pressure from practitioners to accept nursing care procedures, patients can experience pressure from family and friends. Participants in this study were uncertain whether to follow the demands of relatives when making a clinical decision about a patient. Nurses should be aware that a patient's choices about nursing care should be, as far as is possible, his or her own decision.

7.5.7 Principle 7: The validity of a patient's refusal of care should be assessed.

If a patient persists in his or her refusal, nurses should assess the validity of this refusal. The

refusal should be substantially autonomous as discussed in Chapter 1. It should reflect a process of meaningful decision making. It should be informed and reflect the true wishes of the patient. The judgement in the case of C (Re 1994) provides a guide for making this assessment. The High Court held that an adult has the capacity to consent or refuse (is sufficiently autonomous) if (s)he can: a) understand and retain the information relevant to the decision in question, b) believe that information, and c) weigh that information in the balance to arrive at a choice.

There is no evidence in this study that participants assessed the validity of a patient's refusal. This might be due to a lack of understanding of the principles of informed consent and their application to nursing practice. Nurses must ensure that when a patient refuses a care procedure, the refusal is valid. If it is valid it must be respected.

7.5.8 Principle 8: Nursing care should not be administered if a refusal is valid.

Nurses should not administer care if a patient persists in his or her refusal. Nurses should acknowledge that a patient has a right to refuse care procedures. There is evidence in this study that while nurses prefer to proceed with a care procedure with the consent of the patient, they are prepared to do so in the absence of consent. The patient's refusal was regarded as an obstacle to be overcome. Many nurses were mostly prepared to override the refusal if to do so, in their estimation, would benefit the patient. They regarded consent prior to a care procedure as preferable but not essential. Nurses should acknowledge that a patient's refusal should be respected and that this refusal binds the nurses' actions.

7.5.9 Principle 9: The patient's ability to give an informed consent should be assessed

Nurses should make an assessment of whether the patient can make his or her own decisions. The legal ruling in Re C (1994) cited above provide useful guidelines for determining whether a patient can make his or her own decisions. According to Buchanan and Brock (1989) (p80-81) ascertaining the patient's status with respect to competence is of utmost importance because it determines the primary locus of decision making authority. The competent patient is the primary decision-maker regarding his or her own care: legally and ethically the competent patient has the right to accept or reject any form of care or treatment. The incompetent patient does not. It is therefore essential that nurses are able to assess whether the patient has the ability to consent. Furthermore, Buchanan and Brock (1989) (p81) emphasise that the threshold at which patients are considered able to make their own decisions is low; that is most patients will be considered able to make their own decisions about nursing care procedures and should

therefore be permitted to do so. Participants in this study did not articulate how the assessment of patient competence was undertaken. However many participants demanded a high standard of decision making before they were prepared to accept a decision (refusal) to be valid. Interview 26 illustrates this point. Nurses should develop their ability to assess whether a patient has the ability to make his or her own decisions. They should not demand an impossibly high standard of decision making.

7.5.10 Principle 10: Care should be given in the best interests of patients who cannot consent.

Nurses should administer care that is in the best interests of a patient who cannot consent. The participants in this study lacked the assurance that care could be given. They were uneasy about doing so. This unease was exacerbated in the face of opposition from relatives, or perceived opposition from the patient. They were swayed by the influence of relatives and others when administering care to a patient who could not make decisions for himself. This was important because as a consequence, in certain cases, patients did not receive optimum care. While relatives might be able to provide a good indication of the patient's best interests, nurses must be assured that the final responsibility lies with their own clinical judgement.

7.6 Critique of the principles for facilitating informed consent prior to nursing care procedures

The principles identified above have been developed in the light of the theory of informed consent and its application to nursing care procedures, as identified in Chapter 1 and the data set for this study which gave evidence as to how consent is facilitated prior to nursing care procedures. Whether the application of these principles in practice actually will lead to valid consent prior to nursing care procedures needs further research. However some criticisms of the approach advocated are explored in this section. Firstly, a patient orientated approach is advocated. The patient is given as much information as he or she needs in order to substantially authorise a procedure. It is argued that a patient should be offered initial information about what to expect and that the nurse should be prepared to discuss risks and benefits. However, unless standard information giving protocols are developed, the information given is left to the judgement of the nurse. The nurse offers information that he or she perceives to be relevant, but, even with good knowledge of the patient, does not know what the patient needs to know in order to give a substantially autonomous authorisation. It is argued that with discussion and a working relationship (discussed in the following section) with the patient, this subjectivity can be reduced but not eliminated.

Secondly, although it is argued that it is reasonable to consider a patient's implied consent to be valid if it is given in a climate of 'free flowing' information, there can be no assurance that this is so. It remains possible for a nurse to misinterpret the patient's unwilling compliance for implied consent. However given the acceptance of implied consent in law and inappropriateness of more formal consent procedures prior to nursing care, it is argued that it is reasonable for a nurse to consider an implied consent to be valid if it is given in the circumstances outlined in principle 3.

Thirdly, this approach places an onerous responsibility on the nurse. The privilege of assuming that a patient has given his or her consent, a common feature of the nurse patient relationship, is denied to the nurse. Instead the nurse has a positive duty to discuss all care options with the patient, even if only briefly. Furthermore it is the responsibility of the nurse to apply these principles appropriately in clinical practice, rather than adhering to a rigid protocol concerning how much information to give to a patient and when. The overzealous nurse might misread the patient's need for information and give excessive information meanwhile another nurse might give too little information. However it is argued in section 7.9 that nurses must have a thorough understanding of the principles in order to apply them appropriately and effectively in practice. One disadvantage of the approach advocated then, particularly in light of the findings of nurses current understanding of consent, is that a substantial educational effort would be needed if this approach to consent is to be adopted widely. However, as philosophical argument, the regulatory bodies, and to some extent the law demand from nurses that they obtain consent, this can be no argument against adoption of this approach.

7.7 Application of the principles

Acknowledging these criticisms, the usefulness of the principles can be illustrated if they are applied to one of the critical incidents described in this thesis. The following incident describes a situation in which the nurses assumed the consent of a patient to be turned.

Two nurses once presumed they had a patient's consent...they went to move a patient who shouted out, when I went to see why she was shouting, she hadn't been told she was going to be moved...she just shouted "what are you doing" she was a little bit confused. The nurses, when I questioned them, were quite rightly helping the patient change her position, which she needed to do, but didn't think to tell her... Interview 23)

The nurses did not offer the patient any information, nor did they give her the chance to request an explanation of what was to happen, or indeed the opportunity to opt out. If the nurses involved in this incident had offered the patient information, the patient would have had the chance to raise her objection to the care, or indeed she may have had no objection had she been approached in this manner. If the patient did not raise any objection to the care, once informed, the nurses would have been justified in proceeding, reasonably assuming that the patient had implied her consent. Had the patient persisted in her refusal, the nurses could have assessed the validity of her refusal. Further information could have been given to persuade the patient to accept the care. The patient could have been informed about the physiological reasons for regular turning. If the patient persisted in her refusal the nurses could have assessed the patient's competence to refuse. If she was considered to be unable to make a substantially autonomous refusal; if she did not understand the reasons for the care, care could be given in the patient's best interests. Otherwise her decision to refuse care should have been respected.

7.8 The crucial role of the nurse patient relationship

Any understanding of informed consent prior to nursing care procedures must take into account the context within which the care is provided. Crucial to this context is the relationship between the nurse and patient. Many participants recognised the influence of the nurse patient relationship on the way consent should be approached. One participant in a focus group commented on the relevance of consent prior to nursing care procedures:

I just don't know whether it's necessary ... I think people are not just passive recipients of care. I think they have a relationship that's really good, more so than with the doctor ... (Participant in Focus Group 5)

This participant did not consider informed consent to be necessary in nursing because of the relationship of the nurse with the patient. This relationship, in her view, negated the need for informed consent. Another participant developed this idea further. She did not feel that the nurse patient relationship negated the need for informed consent. Instead she felt that the relationship could facilitate the process of informed consent. The participant identified how the patient's agreement to accept the proposed nursing care could be implicit within the context of the nurse patient relationship. The patient's acceptance or refusal of nursing care could be expressed through a well established nurse-patient relationship in which information is given in an informal manner and the patient has the opportunity to ask questions and voice any concerns or objections he or she may have. This view was clearly articulated by the participant who, in

discussion with the interviewer developed her understanding of the concept of consent prior to nursing care procedures.

you develop a relationship and in a relationship you have communication.. it's about getting to know someone, they get to know you and that's how we exchange information and find out what peoples' needs are...and thus they get involved ...the other thing is that people view assessment as a one off, when the patient walks on the ward. I don't agree. It happens all the time, that's why continuity of care is so important...the same person builds on previous information...I feel it's very 'nursing'.

H.A. So would you say that a model for consent would be that it is implicit within nursing, and not a separate thing that you do?

Yes I think that is a really good way of putting it... going to a patient and saying, "do you want a wash today?" I think if you know that person and they know you, you will therefore have given information about what is happening and the plan for the next few days. Therefore, by that relationship, and exchange of information, consent to giving them a wash or the finer details of how they want to do that, is implicit within the information already exchanged...having said that, perhaps one shouldn't be complacent...I still think you need to check out. Their feelings may be different from the last time....but it's about understanding.

H.A. Someone has said to me before that it is based on trust. What you are saying goes further than trust. Trust is very passive. Is trust an element but not enough?

I would agree with you that trust is not all of it... you can have trust because of the uniform...it doesn't mean that you personally have engaged in a relationship
(Interview 18)

The participant in this interview identified how informed consent could be facilitated within the context of the nurse patient relationship. Indeed, the nurse patient relationship is essential to this process. The practitioner and patient work together in partnership in which the individual needs and preferences of the patient can be identified. If the requirement for consent and the quality of that consent are individual to each patient, informed consent can be facilitated only if the individuality of the process is acknowledged. When the nurse has an individual relationship

with a patient, he or she can give information in the amount that is required in the natural course of nurse patient interaction. The process of obtaining informed consent is therefore not a formal exchange of information. It is an informal process in which the nurse and patient discuss the care options in a manner that enables the patient to receive information and to opt out of that care should he or she want to do so. Information is offered to the patient and given in as much detail as he or she requires.

Through communication, the nurse is able to establish the need for further information or to refrain from information giving if the patient chooses to absolve him or herself from the responsibilities of decision making. It is argued that this approach is especially appropriate for informed consent prior to nursing care where the procedures are varied, intimate and likely to have a variable impact on the patient. In view of this, neither the requirement nor the quality of informed consent can be pre-judged. Consent prior to many nursing care procedures may be less appropriately regarded as a separate entity but instead as an integral but identifiable component of the nurse patient relationship..

The essential nature of the nurse patient relationship for the delivery of nursing care is well documented in the nursing literature, (Salvage 1990), (Bradshaw 1996), (Titchen 1996), (Ersner 1996). Bishop and Scudder (1990) describe nursing as the:

Moral practice based on the moral requirement to promote the wellbeing of the patient by caring for him or her by a personal relationship (p104)

The significance of the nurse-patient relationship has been the focus of much discussion. However it has not been discussed in terms of its role in facilitating the patient's consent prior to nursing care procedures.

7.9 A new ethos for facilitating consent prior to nursing care procedures.

Informed consent is required prior to nursing care procedures. This is argued theoretically in Chapter 1. The evidence presented in Chapters 4,5 & 6 endorses this theoretical argument. The violations of patient autonomy identified in this study give practical validation to the theoretical argument that informed consent is a relevant concept in nursing. The principles of informed consent were widely misapplied by participants in this study. Some patients were not informed about the care they received. Others were denied the right to refuse an aspect of their care and had unwanted care imposed onto them. At other times, relatives were given an

inappropriate influence over the care administered to patients. These patterns of care illustrate that patient autonomy can be violated through the administration of nursing care procedures.

Informed consent prior to nursing care procedures is rarely discussed. This is evident in the literature review. Furthermore, the lack of discussion in the nursing literature proved to be an accurate indication of the lack of discussion and application of consent in nursing practice. Many participants in this study were not aware of the role of informed consent in protecting patient autonomy or that patient autonomy could be infringed by nursing care procedures. This link needs to be made explicit. The data in this thesis confirms that the principles of informed consent are not reflected in the participants' approach to patient care.

Nurses need to develop a concept of informed consent prior to nursing care procedures. Principles to define a concept of informed consent have been outlined in the section above. It is argued that the principles of informed consent should influence every nursing care procedure. It is argued that informed consent prior to nursing care procedures is a subtle concept and one that is integral to the administration of care. Central to this process is the continual, but appropriate provision of information according to the needs of the patient but limited by the availability of evidence based information in many instances. Furthermore, the culture of information giving should be the facilitation rather than the restraint of patient choice.

Given the flexibility required to facilitate genuine informed consent prior to nursing care procedures, procedures requiring the patient's informed consent cannot be comprehensively pre-set. It might be reasonable to assume that all invasive procedures infringe the autonomy of a patient and therefore require the patient's informed consent. However it is not possible to pre-identify all procedures that if undertaken will infringe patient autonomy. There can be no rigid formula to ensure that consent is appropriately obtained. Instead, it is the duty of the nurse to ensure that the patient is informed about all care procedures, in the detail required by him or her and is given the opportunity to opt out of care.

Information should be given initially prior to all nursing care procedures. However the extent of information giving is determined by patient need rather than by strict adherence to protocol. The implications of advocating this integral approach while avoiding the application of a rigid formula approach must be recognised. The approach relies heavily on the integrity and judgement of the individual nurse in a way that strict adherence to a predefined list of procedures that require consent does not. Furthermore, practice that relies on the integrity and

judgement of the practitioner may be difficult to monitor. If informed consent is obtained by the principles identified above, rather than by protocol, the enactment of these principles are not readily open to outside scrutiny. Much consent prior to nursing care procedures will be obtained by implication within the context of the nurse-patient relationship. The way in which consent is obtained is self-regulated by the individual nurse.

It can be anticipated that this approach may not be easily swallowed by N.H.S management, who are accountable for clinical standards in the light of the demands of clinical governance (Department of Health 1997). Should the use of a pre determined set of procedures requiring the patient's consent be introduced, this list should be regarded as an addition to, rather than an amendment to the nurses' responsibilities as advocated in this thesis. Furthermore, if nurses merely adhere to a protocol concerning informed consent rather than understand the need to seek consent, it is possible that they will seek consent in a ritualistic manner rather than undertake care procedures "within a framework of informed consent" as the U.K.C.C. (2000) (p15) demands. It can be argued that, even if it were desirable, the quality of a patient's consent cannot be appropriately regulated by an imposed protocol. Quality of consent can be ascertained only if those involved have a working understanding of the principles of consent and are committed to their appropriate application. This is articulated by Wear (1998). He argues:

I submit...that the valid agendas of informed consent will only be met by clinicians who are sold on and committed to the enterprise. The law (or Trust policy) can never accurately calibrate nor sufficiently motivate the necessary behaviour by itself (p13)

The participants in this study did not demonstrate this commitment to informed consent. As a consequence, principles of informed consent did not infiltrate their practice. The results of this have been documented throughout this thesis. A new ethos of consent prior to nursing care procedures is required. This ethos requires the commitment of nurses to ensure that the principles that define it are applied appropriately.

It might be argued that commitment to obtaining consent prior to nursing care procedures is yet another pressure on the already over-stretched clinical workload of nurses. However, it is questionable whether obtaining consent prior to nursing care procedures is a greater burden to nurses than not doing so. For example, many of the nurses who participated in this study spent a lot of time and energy 'persuading' reluctant patients to undergo a care procedure, in

situations in which it remains doubtful whether the patient's consent was ever truly obtained, (Chapter 5). It is suggested that seeking consent prior to nursing care procedures is unlikely to add an extra burden to the delivery of care. On the contrary, if nurses are confident about how to obtain consent and how to proceed when they face difficulties in the consent process, it can be expected that the anxiety caused by uncertainty, evident throughout this thesis, would diminish.

However it is the development of this new ethos that requires time and resources. A culture of consent prior to nursing care procedures needs to be developed within nursing. The concept needs to be subject to discussion and scrutiny. It is the development of an understanding of consent within nursing that is costly in terms of education and awareness raising, (Holm 1997) (p175). Furthermore, the cultivation of an ethos for obtaining consent prior to nursing care procedures is clearly a developmental process, which will take place over time.

A new ethos of consent prior to nursing care procedures is required. This ethos requires nurses to move away from the prevailing attitude; that nursing care will be delivered come what may, towards a culture that respects the patients' right to be informed, to be given a choice and to opt out of care should he wish to do so. To do so would bring nursing practice in line with current health care policy which emphasises patient choice and provider accountability.

Most importantly, nurses should be committed to this new ethos. It should originate from within the profession. Indeed it can only be sustained if nurses are committed to the principles upon which the ethos is founded. In view of this, the ideas and evidence in this thesis will be widely disseminated through journal publication. They require close examination and scrutiny by members of the nursing profession. Their specific application to nursing practice needs to be discussed. The systematic appraisal of these ideas could be most usefully facilitated through focus group discussion. Discussion, as opposed to individual review would be an invaluable way to generate insights as to the relevance, usefulness and feasibility of the ideas presented in this study.

The UKCC (2000) require that nursing care procedures be undertaken within a 'framework of informed consent' (p15). They are right to demand this. The arguments presented in this thesis commend this view. However, at present the U.K.C.C. would be unrealistic to expect it.

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V APPENDICES

Appendix 1: Letters to the UKCC and RCN requesting information about any ongoing work on informed consent in nursing.



United Kingdom Central Council
for Nursing, Midwifery and Health Visiting

Ms H Aveyard
18 Birmingham Road
Stoneleigh
Coventry
CV8 3DD

8 July 1997
KN/C/PE/F1.3
Direct line: 0171 333 6542
Fax No: 0171 333 6538

Dear Ms Aveyard

Consent to Treatment

Thank you for your letter of 2 July 1997. I am unaware of any current work regarding consent prior to performing nursing procedures.

The UKCC, as the regulatory body for nurses, midwives and health visitors, requires its registrants to obtain consent from the patient/client prior to the delivery of any care or treatment. I would draw your attention to sections 26-37 of the booklet *Guidelines for professional practice* (copy enclosed) which discusses the issue of consent in some detail.

I hope this will be of use to you.

I wish you success in your studies.

Yours sincerely

Katrina Neal
Professional Officer, Adult Nursing

Enclosure

General Secretary:
Christine Hancock

Patrons:
Her Majesty the Queen
Her Majesty Queen Elizabeth
the Queen Mother
Her Royal Highness
the Princess Margaret
Countess of Snowdon

20 Cavendish Square
London W1M 0AB
Telephone 0171 409 3333
Fax 0171 647 3435

Ms H. Aveyard
18 Birmingham Rd
Stoneleigh
Coventry CV8 3DD

28.7.1997



Dear Ms Aveyard

Thank you for your letter of 2 July concerning your Ph.D. and the issue of consent within nursing practice. It sounds like a fascinating topic for a thesis but I don't envy you the task!

I am afraid I do not know of anyone who has worked specifically on the issue of consent in nursing practice, nor of any published work on the matter. I assume that you have gone to all the usual sources during your literature search, such as the RCN library, King's Fund library and Senate House and that if you have and have not found any referency to the topic in any of them, there lies the basis of future work for you and the RCN!

There are two people who I know have an interest in matters of consent in nursing, who are Verena Tschudin and Di Marks-Maran. Verena can be contacted at the University of East London where she is a senior lecturer and Di can be contacted at the Thames Valley University, telephone number 0181 967 5477. I hope they may be able to help you in your quest.

With regard to the matter of contact and involvement with the Forum, we plan to run a number of conferences in the next two years which we hope to move around the country, so please do try to come to one (or more). We are also in the process of trying to establish a network of local ethics interest groups but are currently waiting to see how the branch reorganisation will work out so we can try to tap into their resources. We will be in touch about progress made on that front, via our newsletter which I hope you receive.

I hope the above is helpful and that you are successful in your search. Please do contact me again if I can be of further assistance.

Yours sincerely

Jo Douglas
Chair - RCN Ethics Forum

Appendix 2: Letter permitting access to an academic institution to hold focus group study

OXFORD
BROOKES
UNIVERSITY



Helen Aveyard
18 Birmingham Road
STONELEIGH
Warwickshire
CV8 3DD

Level 4 Academic Centre
John Radcliffe Hospital
Headington Oxford OX3 9DU

Tel: 01865 221568 (Direct Line)
01865 221561 (Secretary)
Fax: 01865 220188

Professor Helen Bartlett BA MSc PhD RGN RHV
Director of Research

25 November 1996

Dear Helen

The Nursing Assessment of a Patient's Capacity to Make Decisions

Thank you for submitting a copy of your PhD proposal. I am pleased to inform you that it has been approved by the School's Research Committee. One proviso, however, is that participants should be given the right to opt out of the sessions at any time.

Wishing you all the best with this interesting study.

Yours sincerely



Professor Helen Bartlett
Director of Research

cc: Ms Jo Atkins, SHCS

Appendix 3: Notices of ethical approval

Manor House
Headley Way, Headington
Oxford OX3 9DZ

Tel: 01865 222692/222547
Fax: 01865 222699

Our Ref. LC/ Agr/97.035

15th August 1997

Ms Helen Aveyard
18, Birmingham Road
Stoneleigh
Warwickshire
CV8 3DD

Dear Helen,

Re: NAPREC 97.035 - Does Informed Consent Theory Usefully Inform Nursing Practice? The Development of a Model for the Practise of Obtaining Consent to Nursing Care Procedures.

Thank you for your application which was considered at the August meeting of NAPREC. The Committee raised the following points.

- i) The Committee wondered if it would be useful to focus on critical incidents in clinical practice in which the research subject felt that consent was gained inappropriately as well as appropriately.
- ii) Please find attached an annotated version of your letter. I hope that this does not appear to be discourteous - it is a quick way of letting you know the opinions of Committee members. Could you please incorporate the suggested changes (or replace the letter along the lines we have proposed) and let me have a final version.

Once I have received satisfactory responses to the above I will be happy to give you Chairman's approval.

Yours sincerely,

Austin B. Riches

Mr Lindsey Coombes
Chairperson
Nursing and Allied Professions Research Ethics Committee

Chairperson: Mr Lindsey Coombes

Birmingham

HEALTH AUTHORITY **South Birmingham Local Research Ethics Committee**

Room 36, First Floor, Therapy Centre, Selly Oak Hospital, Selly Oak, Birmingham B29 6JD

Telephone Nos 0121 627 8734 & 8733 - Internal Extensions 53747 & 53737

Facsimile No 0121 627 8575 - Internal Extension 53751

Committee 1

Chairman: Dr R W Jubb at above address

RWJ/mbt/jb

4 December 1997

Please Quote:3981

Ms H Aveyard
18 Birmingham Road
Stoneleigh
Coventry CV8 3DD

Dear Ms Aveyard

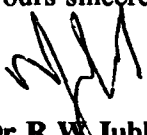
REC reference number 3981

Does Informed Consent Usefully Inform Nursing Practice?

Thank you for your letter dated 24 November 1997 enclosing the modified Information Leaflet that you wish to use in your Study.

I have had a chance to review this and I am happy to give Chairman's Approval and I wish you well with your Study.

Yours sincerely



Dr R W Jubb
Chairman
Local Research Ethics Committee

Appendix 4: Letters permitting access to a clinical area to carry out critical incident study



University Hospital Birmingham

NHS TRUST

Sharon Goodman
Director of Nursing and Quality
Telephone No: 0121 627 8720 Internal 51454
Fax No: 0121 627 8394

Helen Aveyard
18 Birmingham Road
Stoneleigh
Warwickshire CV8 3DD

sg/mab/sg3/97080601
6th August 1997

Dear Helen

Thank you for your letter of 29th July regarding your PhD thesis.

I am very happy for the Trust to be involved. If you would like to send me further information I will gain the support of the Medical Directorate. In the meantime, I would start pursuing ethics approval.

I look forward to hearing from you soon.

Yours sincerely

SHARON GOODMAN
DIRECTOR OF NURSING AND QUALITY

*Nurse
Torve*

*Research Ethics
Committee*

THE CENTRE OF EXCELLENCE

Oak Tree Lane, Selly Oak, Birmingham B29 6JF Tel: 0121 432 3232



**University Hospital
Birmingham**
NHS TRUST

Teresa Finlay
Head of Practice Development
Ex. 53834

Ref: 97090205

3rd September 1997

Helen Aveyard
18, Birmingham Road
Stoneleigh
COVENTRY
CV8 3DD

Dear Helen

Sharon Goodman has handed the details about your PhD research proposal to me. I was most interested to read it for two reasons:

- firstly it's great to hear of some interesting **nursing** research being carried out within the Trust particularly at this level.
- secondly I notice that Jenny is supervising you! We are 'students' at the same educational establishment!

I would very much look forward to meeting you to share your experiences and to discuss the study when you do get ethics Committee approval. So do contact me in the future when you do get approval. If you have any other queries I would be happy to help you with them.

I look forward to meeting you.

Yours sincerely

Teresa Finlay
Head of Practice Development

THE CENTRE OF EXCELLENCE

Oak Tree Lane, Selly Oak, Birmingham B29 6JF Tel: 0121 432 3232
Chairman: Dr. Malcolm Skillicorn Chief Executive: Dr. Jonathan Michael



University Hospital Birmingham

NHS TRUST

THE LIVER & HEPATOBILIARY UNIT
Bob Hibberd, Senior Nurse Manager
3rd Floor, Nuffield House, Queen Elizabeth Hospital
Tel: 0121 472 1311 Ext 3216 or via
Mobile: 0498 668828
e-mail: Bob.Hibberd@university-b.wmids.NHS.UK

Ref: RH/dajm

15 December 1997

Ms Helen Aveyard
18 Birmingham Road
Stoneleigh
Coventry
CV8 3DD

Dear Ms Aveyard

Further to your letter of 1st December 1997, I confirm that I have no objection to our nurses participating in your study and I am happy for you to go ahead as planned.

I would be very interested to receive more details about your work and also would very much like to see the results when you have completed your research.

Best wishes.

Yours sincerely

BOB HIBBERD
SENIOR NURSE



**University Hospital
Birmingham**
NHS TRUST

SG/DCB

8 December 1997

Ms H Aveyard
18 Birmingham Road
Stoneleigh
Coventry
CV8 3DD

Dear Ms Aveyard

Thank you for your letter concerning the interviewing of nursing staff in the Neuroscience Directorate.

I am very happy for these interviews to take place and wish you well with your research.

Yours sincerely

D. Bolton.

PP

**SUE GRAY
SENIOR NURSE MANAGER
NEUROSCIENCE DIRECTORATE**



***University Hospital
Birmingham***

NHS TRUST

RENAL & UROLOGY DIRECTORATE

Telephone No.: 0121-472-1311 Fax No.: 0121-627-2433

Our Ref: MCH/RSB80

4th December 1997

Ms Helen Aveyard
18 Birmingham Road
Stoneleigh
Coventry
CV8 3DD

Dear Ms Aveyard

Thank you for your letter dated 1st December concerning your studies for your Ph.D.

I am pleased that we can be of help to you in this study and would be very interested to see the results.

Please let me know if you need any further assistance.

Yours sincerely

R.S. Bird

pp Marie Hamilton
Senior Nurse Manager

c.c.: Sister L Willetts E4B

Dear

**I Appendix 5: Letter sent of invitation sent to potential participants in critical
incident study**

PhD Study: Does Informed Consent Usefully Inform Nursing practice?

I am writing to ask whether you may be willing to help me with my research which I am undertaking as part of my Ph.D. at the Nursing Studies Department at King's College, London. The topic of my research is the informed consent process in nursing. The research has two stages; firstly to explore how consent to nursing procedures is currently obtained; secondly, to explore how consent could/should be gained for nursing care procedures. The overall aim of the study is that, through consultation with nurses, a model for gaining consent to nursing care procedures can be developed.

I am presently working on the second stage of the study. I am carrying out in depth discussion interviews with nurses in general medical wards to explore ideas as to how consent could or should be gained to nursing care procedures. In order to do this, I am using a modified form of the Critical Incident Technique. (Flanagan 1954)

If you would like to participate in the study, I would ask you to identify incidents that arise in the course of your clinical practice in which consent to nursing care procedures is significant. I would suggest that you note down any incidents that arise for two days preceeding the interview and these would form the basis of discussion from which we would try and establish the components of good practice. What amounts to 'significant' would be left entirely to your discretion. Incidents discussed can be reflective of either good or bad practice. If you are willing to participate in the study, I can explain this in further detail.

With your permission, I would tape record the interview which would last about half an hour. Transcripts of the tape would be anonymous and could not be attributed to you. The tapes would be erased once transcribed. You would be free to discontinue the interview at any stage.

I hope you will be interested in participating in the study. Please do not hesitate to contact me if you require further information,

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II Appendix 6: The administration of sedatives to a patient who is unable to consent

Further examples of participants' unease caring for patients who cannot consent were given in critical incidents concerning the administration of sedative drugs to patients who were aggressive or violent. These incidents do not fall directly into the remit of this thesis, given that the administration of the sedative could be regarded not strictly as a nursing care procedure, but as a necessary reaction to an unfortunate series of events. In addition, the sedation might be carried out for the sake of others as well as the patient himself. However, eight such incidents were portrayed by seven different participants, indicating the level of concern such instances arouse. The main features of these incidents will be summarised in order to examine the extent to which they shed light on the way in which nurses care for patients who cannot consent.

The following incident is typical. The participant described an acute situation in which a patient was sedated.

A confused patient wanted to leave the ward. He stripped off all his clothes and he was in the observation bay, naked. He had a chest infection which had made him confused, he wouldn't put any clothes on. The other patients were on cardiac monitors so we couldn't pull the curtains... it was so undignified for him. he began to get aggressive and we got the doctor to see him, he actually got hold of one girl's dress and he ripped it. We got security and we sedated him.

H.A. How did you feel about sedating him?

It's horrible because you feel you are doing it against his will but you have to look at every one else. It was 8pm Sunday, it was getting to nights, there were 3 people on nights, no help around, 22 patients, we had to have their interests. ..his daughter was there. she was very distressed. it wasn't safe for him to be naked in the corridor, on his bottom , so although it was horrible, it had to be done (Interview 11)

Another participant her unease at having to use sedation .

I came onto a night shift and there was a man... who was really confused..., in the middle of the night, he completely flipped.... he was trying to throw things at us, trying to break the windows, very violent, very aggressive, we were unable to restrain him as far as being able to prevent him from harming himself. we had to call security... it was

upsetting because he was a proud man, very nice, usually, but just... he was shouting, it was awful, ...he was adamant that he wouldn't have the injection and that we would have to do it against his own will...which is an awful thing to have to do . it has happened before and it is often on night duty... for this particular man, the whole ward was disturbed, we were frightened he was going to go through the window, he was in such a state... you could tell by the look on his face that he was frightened... it was a very difficult situation it was awful....we gave it to him... we had to, with the security man we had to restrain him, by this time we were frightened he was going to hurt himself.. so unfortunately he had to be restrained, we held his arms and legs, which is an awful thing to have to do

The participant described how in her view, the sedation of a patient was not consistent with the duties of a nurse:

In his mind it was so real, he thought we were trying to harm him...it was so real for this gentleman . It felt like you were doing something wrong to him although our intentions to him were not... to him...and that makes you feel, you come not this job to do good and that makes you feel...

H.A. What was it about the incident that was so upsetting?

I think ...the upsetting part, it was against his will, I can't remember his words but he was very angry he thought we were trying to kill him basically... and the thought of somebody thinking that ... if he'd said yes ok I'll have the injection, but was still aggressive...we tried to explain what we were trying to do, to get some sort of consent, but it just wasn't possible... I think it was the, I felt we were going against what he felt was right at the time, whether or not it was rational, it was real to him... that was the worst bit really (Incident 5)

Nurses' unease concerning the sedation of a patient was the common factor occurring in all of the eight incidents. All participants found the use of sedation distressing and hence it was identified as a critical incident. It is interesting to note that the participant who described Incident 5 (above) could not reconcile the use of sedation with her role as a nurse. To her the two were irreconcilable. Despite the feelings of great unease, most participants who described the use of sedation did feel that it was justified; that there was really no other appropriate

course of action. However two participants described incidents in which she did not feel the use of sedation was justified. They felt that the patient's care had been badly managed and that other more appropriate measures could have been taken. The incident described by one participant is presented below:

A lady was ransacking the whole department, endangering the nurses.. patients.. I remember being called to give this injection, as they were holding her down... what do you do... I passed the buck, only for my own comfort....

H.A. Why did you do that?

*For my own legality reasons really...it had to be fast acted on, I was a student, although there was a danger, I wasn't happy to give this stuff, it wasn't drawn up.... I have to have informed knowledge to give it and if I don't, I act unprofessionally and dangerously. I didn't know the unit, or the patient, I think it was unfair that they asked me.. afterwards we spoke about it
...there were a lot of patients hanging around, I took them away..making it a safe environment...I'd seen it before but this more distressing..it was the sheer force and noise... you could see her getting progressively worse nothing was done about it until.. maybe something preventative...she knew what was going on, she'd been in the situation before, but no discussion...*

In addition to her inexperience, she felt that the situation could have been managed better; with action taken sooner:

H.A. How do you feel it could have been managed?..

Managed earlier ..but I suppose the incident could have been better controlled, it was in the corridor, in view of other patients, I think if they hadn't done it then she would have got worse... should we really be doing this? I think there is a fine line btw violence and restraint and what I saw wasn't really restraint..it was harder.. it was just force... I think it was all they could do in the circumstances... (Interview 8)

It might be argued that to feel unease about the administration of sedation to a patient is appropriate. Such unease is a safeguard against the use of sedation for trivial reasons. However

this unease may be exacerbated by lack of understanding of the principles that might justify the sedation of a patient under appropriate conditions.